A Readiness Review Report For Implementation of Self-Determination/Person Centered Planning Based Supports for Community Living Waiver:

Models and Findings Report

DRAFT

Commonwealth of Kentucky

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I. Introduction

The Commonwealth of Kentucky (Commonwealth) is eqploring a statewide initiative to shift the focus of support services for people with developmental 'disabilities from a program capacity-based system to a person-centered approach, with an emphasis on being consumer driven, family oriented, choice based, and market focused. To approach this initiative, the Kentucky Department of Medicaid Services, Division of Long Term Care, contracted with William M. Mercer, Incorporated (Mercer) to conduct a study of the readiness of implementing self-determination as part of its Supports for Community Living (SCL) waiver. The key elements of the study are:

- Conduct a comprehensive assessment of the political and social environment,
- Determine and recommend, options for applying self-determination principles,
- Develop a detailed model of self-determination from the selected option,
- Design a detailed implementation plan to include budget and timelines, and
- Provide a review and compare the Commonwealth'smodel of self-determination with approaches used by other states.

The study was initiated in May 2001. Key activities included SCL site visits and readiness reviews, operational and financial rate reviews of the SCL program, and consumer outcome and interest surveys. In addition, Mercer staff met with KARP and KARR community leaders, the House Bill 144 Commission, and Olmstead planning group members at the beginning of the study and received guidance and feedback about similar self-directed service initiatives underway.

Assessment Criteria

During discussions with state and community leaders, Mercer recognized that significant work has already been accomplished in the Commonwealth in the area of self-determination and self-directed services. Values and principle statements by the HB 144 Commission and the Olmstead planning group outline a clear vision and direction for the Commonwealth, and both the mental retardation authority and the Medicaid authority have hosted focus groups and constituted work teams to identify implementation opportunities. The Kentucky Developmental Disabilities Council conducted consumer and family workshops by the Center on Self-Determination (Tom Nearney) during the time of the Mercer study. In assessing the Kentucky SCL program readiness for self-directed services, Mercer, therefore, focused on key management tools and activities that are essential for the implementation of these values and principles

To develop these self-determination assessment criteria, Mercer employed members of the State of New Hampshire Area Agency Monondack County self-determination team (Ric Crowley, M.A. and Robert McCaffrey, PhD) who designed and implemented the first self-determination effort in 1991. Mr. Crowley was later employed by the Robert Wood Johnson Foundation (RWJ) in 1995 through 2000, to provide technical assistance to seventeen states that were awarded grants to pilot self-determination initiatives. In addition,, Mercer employed Jim Conroy, PhD, and the Center for Outcome Analysis, to identify the components of self-determination. Dr. Conroy

is retained also by the RWJ and the Centers for Medicare and Medicaid Services (CMS) to design and conduct personal outcome measurement on self-determination. Mr. Crowley and Dr. Conroy defined the self-determination components for the Kentucky study. These management components were then reviewed by a team of previous state directors from California (Denny Amundsen), Texas (Richard Smith, PhD), Arizona (Roger Deshaies), Washington State (Norm Davis), West Virginia (Rob Hess, PhD), and Alabama (Billy Stokes, EdD) to determine their application to state operations. Mercer's findings and recommendations are based upon the presence of the following self-determination management components:

- **Person-Centered Planning** (PCP)-Planning based on the needs, preferences, and dreams of the consumer, family, and significant others.
- **Individual Budget-In** coordination with the PCP, a budget is developed to support the plan. This budget incorporates individual, community, and family supports, as well as public funds, and serves as the basis for procuring services,
- **Integrated Service Authorization**-Services are authorized independent of the service provider, but in conjunction with the individual budgeting process to expedite service provision. This authorization is tracked against state and federal appropriations, and is subject to audit/other fiscal accountability tools.
- **Flexible** Purchasing-Flexibility with the State contracting/procurement process, which allows the consumer and family to be creative and cqst-effective in their service development.
- **Portable** Rates-Assuming the rates for service are relatively equitable, the consumer/ family can select their provider and move between providers to receive the best possible service.
- **Fiscal Intermediaries-Legal** entities that provide a variety of financial services to support flexible choices for the consumer/family (e.g., pay bills, track individual budgets, assist consumer/family in acting as "employer of record," etc.).
- **Support Coordinators/Service Brokers—Individuals** who are independent of the service provider network and can help consumers and families develop service plans and budgets, prioritize and select services, negotiate with potential providers, and/or develop new support alternatives.
- **Personal** Outcomes-Quality of care (health and wgllness, safety/freedom from harm, stable home and work situations, quality of staff support) and quality of life (consumer satisfaction, community inclusion, friendship, and status) are measured by specific outcomes in planning and, as the service is provided, compared to several surveys of satisfaction.
- **Personal Relationships and Supports—**Planning encourages the development of personal relationships and "circles of support" for the consumer, including the larger, non-disability community.
- **Integrated Licensing/Certification**-To ensure individual health and safety, licensing and monitoring activities are simplified and focused on the primary personal outcome measures.

Assessment Process

Twenty-five (25) providers were selected randomly and approved by the Department of Medicaid Services, Division of Long Term Care for on-site visits and readiness reviews. Program monitoring and evaluation findings from the most recent Department of Mental Retardation surveys were reviewed, and financial rates and cost survey data were collected by Mercer staff. Mercer site visit staff consisted of former state developmental disabilities directors from California, Arizona, Texas, Alabama, West Virginia, and Washington, a HCBS provider agency director from Arizona, and staff who designed and operated the Monondack County self-determination initiative for the State of New Hampshire. Representatives from the Kentucky Office of Long Term Care and Department of Mental Retardation reviewed and approved the readiness review survey instruments, and also accompanied the Mercer site visit teams. Provider readiness review survey instruments are attached to this report.

Mercer actuarial and financial analysis staff conducted SCL operations and financial reviews of the state Medicaid and mental retardation administrations. Interviews were conducted with Kentucky Medicaid and mental retardation leaders and key staff. These reviews examined the current delegation of organizational responsibilities and program monitoring and fiscal management systems. Practices reviewed included enrollment and eligibility determination, individual service planning, service authorization, purchasing and procurement, reimbursement and rate setting, and outcomes and quality assurance. Findings were then reviewed by Mercer staff who were former state Medicaid administrators from Arizona and Florida, and examined for consistency.

In addition to the provider site reviews and SCL operations assessments, Mercer retained the Center for Outcomes Analysis (COA) to examine consumer interest and establish baseline data on individual and family outcomes. COA has developed longitudinal data on personal outcomes for over 40,000 people with developmental disabilities living in 28 states. The COA findings serve as the baseline data for comparison with other states that have initiated self-determination pilots.

The Consumer Quality of Life (CQL) Index was originally modeled after Seltzer's (1980) instrument which was, in turn, derived from portions of the Multiphasic Environmental Rating Procedure (Moos, Lemke & Mehren, 1979). It is a measure of how home-like and pleasant the setting is. It is completed after the visiting data collector has walked through the residence, rating each room on dimensions such as cleanliness, odors, condition of the furniture, individualized decorations, and overall pleasantness. Inter rater reliability of the CQL was reported as .81, with test-retest at .70 (Devlin, 1989). Mercer distributed the CQL assessment instrument developed by COA to all SCL consumers. Survey responses have been collected and the findings are included in Section IV. A summary of COA research for other states and sampling methodology are also attached to this report.

II. Comparison of Kentucky Services with Selected States

The Commonwealth presents an interesting situation when compared to other states. The Commonwealth reflects national trends in employment, poverty levels, and health insurance coverage. It is unique, however, in the extent of its rural population and it is this uniqueness that presents the management challenges to providing social services. Based upon studies of calendar year 2000 data conducted by the Henry J. Kaiser Family Foundation' published in June 2001, more people in the Commonwealth live in rural settings than in metropolitan communities. From the report, the metropolitan/rural distribution of people in selected states is as follows:

TABLE 1: Metropolitan/Rural Living Arrangements

State	Percent of People living in Metropolitan communities	Percent of People living in Rural communities
US Average	81 percent	19 percent
Kentucky	46 percent	54 percent
Tennessee	70 percent	30 percent
Ohio	83 percent	17 percent
Indiana	59 percent	41 percent
Missouri	76 percent	24 percent
Iowa	47 percent	53 percent
Alaska	46 percent	54 percent
Montana	22 percent	78 percent
West Virginia	53 percent	47 percent
Arkansas	49 percent	51 percent
Virginia	78 percent	22 percent

With over half of its citizens living in rural settings, the Commonwealth has developed strong and stable communities, with significant family and cultural histories. At the same time, the distance between social agencies and people needing support has created logistical and economy of scale issues.

In other ways, the Kaiser Foundation study found that the Commonwealth is similar to other states. The distribution in size of the Commonwealth's employers is almost identical to the national average. The following table compares the size of employers in selected states.

[1] *Reference data can be located at www.statehealthfacts.org*

TABLE 2: Size of Emnlovers

State	Companies with 1-9 Employees	Companies with 10-24 Employees	Companies with 25-99 Employees	Companies with 100-499 Employees	Companies with 500-999 Employees	Companies with 1000+ Employees
US Average	20 percent	9 percent	13 percent	14 percent	6 percent	38 percent
Kentucky	20 percent	9 percent	12 percent	14 percent	5 percent	40 percent
Indiana	18 percent	10 percent	14 percent	16 percent	6 percent	38 percent
Missouri	18 percent	8 percent	13 percent	15 percent	6 percent	39 percent
Iowa	22 percent	10 percent	14 percent	14 percent	6 percent	34 percent
Tennessee	21 percent	8 percent	11 percent	13 percent	4 percent	42 percent
Ohio	16 percent	9 percent	13 percent	16 percent	5 percent	40 percent
Georgia	18 percent	9 percent	11 percent	12 percent	7 percent	44 percent
West Virginia	21 percent	7 percent	14 percent	15 percent	5 percent	38 percent

With regard to people living in poverty, the Commonwealth reflects the national average. Using the standard of 200 percent of the Federal Poverty Level (FPL), the Kaiser Foundation 2001 study found that the US average for low-income people is 35 percent of the working age population. The Commonwealth's experience is very similar with 37 percent of the working age population below the FPL. By comparison, neighboring states such as Virginia's low-income population represents 29 percent while West Virginia is 45 percent, The Commonwealth ranks 32nd in median family income with $30,620 per family. The national median family income is $33,154. Median family income in bordering states range from Virginia, which is ranked 7th nationally ($37,125 per family), to West Virginia, which is ranked 50th nationally ($25,258 per family), and Arkansas, which is ranked 5 1st nationally ($24,998 per family).

Within the SCL program, the Commonwealth has experienced a significant growth and is ranked 7th nationally in spending at $53,919 per Waiver participant. Based upon the 1997 Medicaid HCBS Services and Supports for People with Developmental Disabilities published by the National Association of State Directors of Developmental Disabilities Services [2] (NASDDDS) (Robert Gettings and Gary Smith), and updated from the Kentucky DMA Waiver Cost Summary fiscal management reports, SCL enrollment and expenditure trends are as follows:

TABLE 3: Kentucky SCL Enrollment and Expenditure Experience

Fiscal Year	Number of Participants	Cost Per Participant	Total Expenditure
1990	763	$18,110	$13,818,800
1992	833	$29,162	$24,292,000
1994	855	$25,691	$21,966,200
1995	855	$30,084	$25,722,000
1996	855	$44,830	$38,337,400
1997	1086	$42,830	$42,317,100
1998	1032	$40,169	$41,373,900
1999	1056	$43,497	$45,932,900
2000	1279	$47,249	$60,43 1,900
2001	1292	$53,919	$69,663,600

[2] *Report available through NASDDDS 113 Oronoco Street, Alexandria, VA 22314*

The developmental disabilities service system in the Commonwealth is also unique in that it has among the highest utilization of people living in residential settings of 16 persons or larger. The most recent comparative data based upon the 2000 State of States[8] report published in January 2000, by the University of Illinois (David Braddock, et al) captures information through 1998. This study cites that 62 percent of residential placements offered in the Commonwealth are in settings of 16 beds or larger. The Commonwealth ranks last having the largest number of people in large residential settings. By comparison, Vermont is ranked first with two percent of the people living in settings larger than 15 beds, and New Hampshire is ranked second with only four percent residing in such settings.

People with developmental disabilities enrolled in the Commonwealth's support system share similar demographics with their peers in other states as reported in the 2000 State of the States report (Braddock, et al). The slight majority of the Commonwealth enrollees are male. The average age for people enrolled in the service system is 41 years (national average) and the Commonwealth's average is 40.7 years. The Commonwealth is similar to other states in terms of the number of people who are verbal and are mobile. The Commonwealth has a lower reported need for medical care among the people enrolled. The Commonwealth is similar to other states in terms of the percentages of people with developmental disabilities who also present behavioral challenges. The Commonwealth and Virginia have the lowest percentage of people with mild mental retardation as the primary diagnosis for people enrolled.

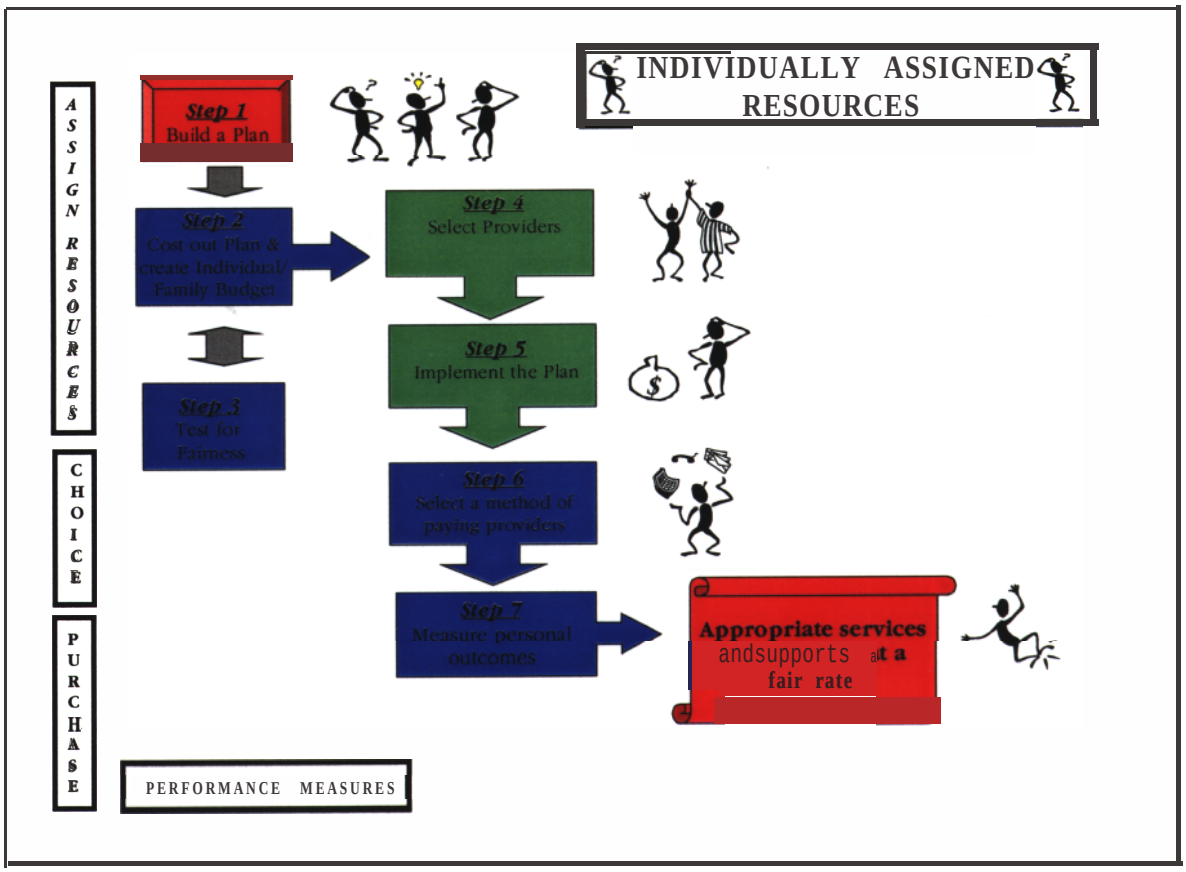
It should be noted that data from the 2000 State of the States report capture information up to 1998. Based on the DMS expenditure report for SFY 2001, the Commonwealth currently expends more for people living in community settings than it does for people residing in the ICF/MR program. Concomitantly the number of people residing in ICF/MR is decreasing as the number of people living in community settings increases.

[3] *Braddock, David; Hemp, Richard; Parish, Susan; Rizzolo, Mary: The State of the States in Developmental Disabilities:2000 Study Summary, University of Illinois at Chicago, July* 2000

III. Models of Self-Determination

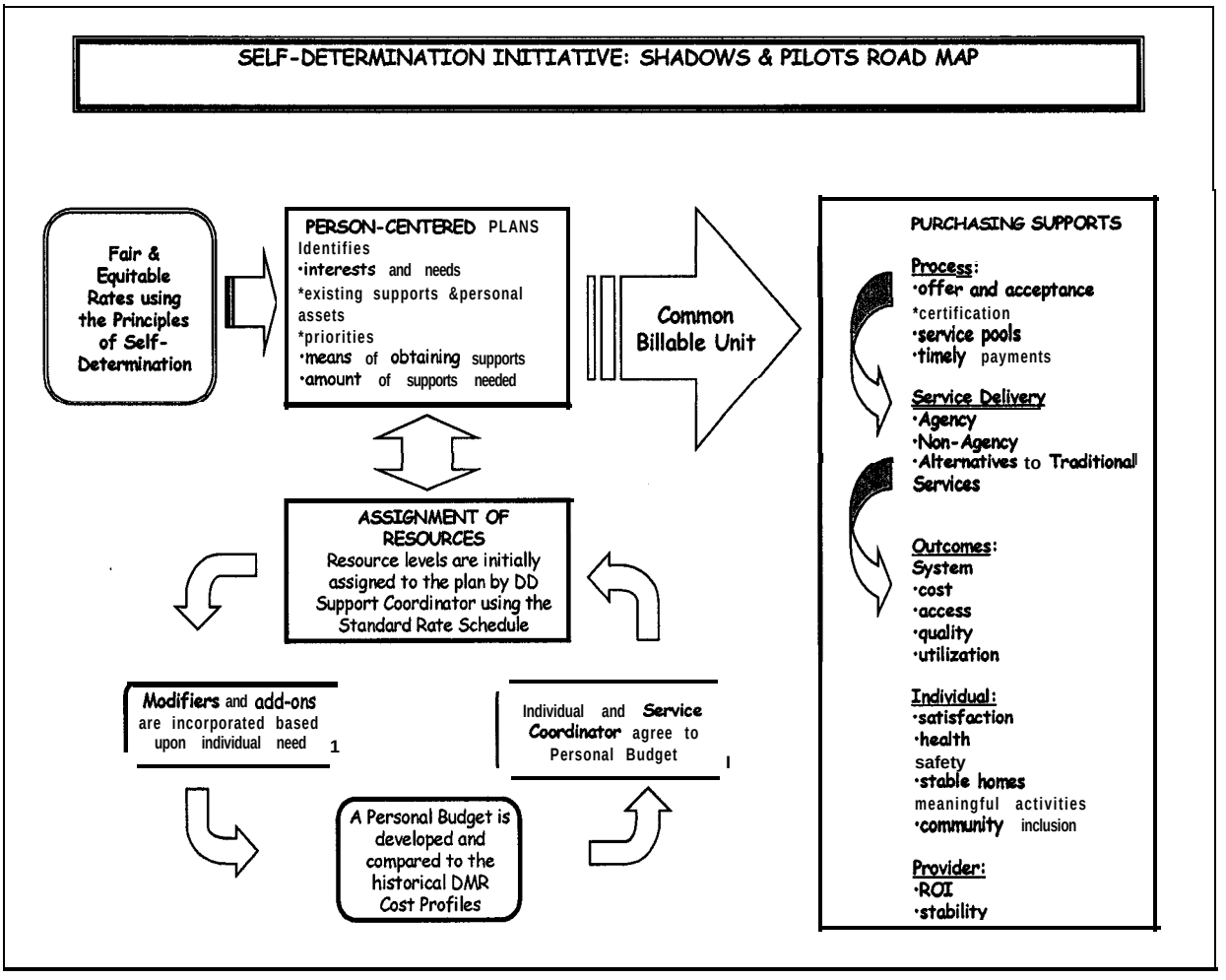
The system of supports and services for people with developmental disabilities continues to evolve as states pilot self-directed services. The new generation of services is fostering certain major shifts in expectations and with service delivery. In the past, the focus with most systems of support was centered around an emphasis on a range of services, usually with Intermediate Care Facilities for people with mental retardation (ICF/MR) services anchoring one end of the continuum and independent living the other end. The theoretical framework had people with developmental disabilities moving along this continuum, ideally towards the independence scale. Each point along this continuum has set supports usually with bundled services. For example, if the point on the continuum was a group home, then all the services associated with that point are available, almost irrespective to whether or not all the services are needed or wanted.

The new generation of services articulates a different vision. The core centers on the belief that services and supports should be individually tailored and with more reliance on community networks and inclusion rather than the continuum of support model. The new generation of services and supports are often referred to as self-determination or consumer-directed supports. The following diagram illustrates how consumer-directed supports operate.



The most often cited origin for consumer-directed supports is an Area Agency in Monondack County, New Hampshire and the concomitant involvement of RWJ. The efforts to empower people with developmental disabilities to take an active and controlling involvement in decisions about their lives and implementation of individual budgets has spurred the consumer involvement movement not only in New Hampshire but also across the country. RWJ's commitment to fund demonstration projects throughout the country has provided the resources for several states to examine and remove system barriers, thereby supporting the changes in systems necessary to truly implement consumer-directed services.

There are many barriers that mark the introduction of self-directed services. Many of the barriers are to be expected as new practices begin to replace old and new expectations begin to push for more rapid change. The selection of a service delivery model to implement consumer-directed services is dependent on the management framework that exists in the current Commonwealth system. Specifically, RWJ evaluators found in the "1999 System Reform Evaluation," (Ric Crowley) that the relationship between rate methodology, contracting and procurement, and person-centered plans is critical. The following flow chart describes the relationship of service authorization, rate methodology, procurement, and service planning in a self-determination model (Arizona Division of Developmental Disabilities, 2000).



"Consumer-directed" and "self-determination" have become the terms used to describe a new generation of services and supports focused on individual choice of services. As such, the terms reflect a differentiation from provider-directed services that limits individual choice to a facility or agency's capacity. The term is used to describe:

- An advocacy movement promoting changes in policies and services;
- Citizenship and the rights of being a citizen encompassing the idea of inclusion, control, choice, freedom, opportunity, and accountability;
- Family support;
- A new point on the continuum of services;
- A new way to manage public funds often tied to a shift in accountability towards families and individuals with developmental disabilities;
- A way to reduce cost, since some anecdotal experiences indicate that decisions made by people with developmental disabilities or their families tend to be less costly than those made by professional staff;
- A way to reduce waiting lists is often associated with shifts in cost and a belief that consumer-directed supports creates opportunities to expand the provider network; and
- A set of skills.

There is no one-service delivery model that encompasses the entire range of consumer-directed support services. In general, the following components must be present to be considered consumer-directed:

- The person with developmental disabilities has choice and control over identifying their service needs and developing the service plan;
- The person with developmental disabilities has choice and control over the hiring and/or selecting their support worker(s);
- The person with developmental disabilities has choice and control over the terms and conditions under which the supports are provided; and
- The person with developmental disabilities has choice, control, and responsibility to manage the duties of an employer or to purchase the administrative responsibilities associated with being an employer in particular for employment taxes and payroll;

The person with developmental disabilities has the choice, control, and responsibility to supervise, discipline, or terminate the worker providing their supports. The use of consumer-directed services can be easily misunderstood unless there is an agreed upon definition on how the term will be used. This model defines consumer-directed as transferring the decision-making responsibilities to people with developmental disabilities for the services and supports provided. The decision-making responsibilities include control over funds, an option to change service providers, the ability to set their own life goals, and the ability to shape how services are provided to ensure that their individual preferences and objectives are being addressed rather than system needs. Essential to individual choice is the presence of an independent service broker/support coordinator. The following table illustrates the relationship between case management and other forms of individual support:

CASE MANAGER - Comparisons with Other Roles

	CASE MANAGER	SUPPORT COORDINATOR	PLAN FACILITATOR	COMMUNITY GUIDE
What do they do?	• Authorize for each person the amount of public funds and/or service levels • Arrange and lead the ISP process • Assign people to a provider • Conduct periodic reviews of case plans and provider quality • Authorize payment to providers	• Authorize for each person the amount of public funds and/or service levels • ***Assists the Individual / Family to lead the ISP process*** • ***Arrange for choice*** and assign people to a provider • Conduct periodic reviews of case plans and provider quality • Authorize payment to providers	• Assists the Individual / Family to lead the ISP process • Serves as the ***personal advocate*** and counsel to the individual/family • Provides ***financial management*** assistance to the individual/family • Arranges for choice of providers • Obtains new providers / ***non-traditional supports*** • Provides **guardianship** as needed	• Participates in the ISP process as a ***community resource expert*** • Identifies local resources and opportunities for ***non-paid supports*** • Arranges for ind./family ***participation in community*** opportunities • Represents ind./family interests in ***community development and planning activities***
Who usually does this?	• ***State employees*** (usually DMR)	• ***State employees*** • Private agency or person	***Private agency*** or person chosen by the individual/family	***Private person*** or agency chosen by the individual/family
How do they get paid?	• State salary schedule	• State salary schedule • State contract	• State contract • Individual Service Agreement	• Individual Service Agreement

Principles of Self-determination

Consumer-directed services could be defined with a limited scope to include only a single category of service or be broadly defined to encompass all possible supports. Irrespective of the definition that is adopted, there are several common elements that comprise consumer-directed services. They follow:

- Freedom to choose providers and the authority to make such decisions are central components;
- Control over resources including individual budgets and the freedom to select the manner in which services are provided;
- The support services flow from a plan that reflects the desires, wants, expectations, and aspirations of the person with a developmental disability. The plan in simple language is a statement of what the person wants to do and with whom they wish to associate;
- Assessments and evaluations are exclusively tied to the person's desires, wants, expectations, and aspiration and not to system needs or someone else's view of the person;
- Self-directed services are truly self-directed. The person with developmental disabilities has the authority to decide, control, and manage the services. The selection of service providers is a cornerstone in this model;
- Services and supports are intimately tied to community networks and inclusion;

- Choice is a function of information that must include all options that are available in order to be truly informed. Substitute decision-making is acceptable in situations where there is truly limitation in a person's capacity to make decisions;
- Choice and decision-making are learned skills refined with exposure to new situations, information, and experience. Consumer-directed services must be respectful of a person's history and possible lack of opportunities to truly engage in informed decision-making; and
- Choice and decision-making are not masks that prevent assurances for personal safety and well-being.

Quality, Risk, and Consumer-Directed Supports

Consumer-directed services and supports have as an outcome a greater reliance on community services and networks. Therefore, the same risks faced by other citizens become an unavoidable consequence of consumer-directed supports. It would be naive for public sector administrators and policy-makers to deny that there exists a belief among the public at large that all services and supports for people with developmental disabilities should be risk free. In fact, many of the existing regulations are the product of incidents, some with horrendous consequences, for people with developmental disabilities. This often results in a catch-22 scenario where consumer-directed services are minimized or prevented due to over-burdensome regulations.

Attached is a summary of research conducted from 1994 to present by the Center for Outcomes Analysis in California around consumer-directed services. The preliminary findings are that people with developmental disabilities that control their own services are at no greater risk than those enrolled in more traditional systems. Consumer-directed services cannot be viewed as an abdication of responsibilities to minimize risk from harm, exploitation, neglect, or abuse. Rather, it is a sharing of responsibilities with the person with developmental disabilities and, when appropriate, with their families to ensure that the following are in place:

- People live and work in clean and safe environments and those who support people with developmental disabilities work under the same conditions;
- People are safe from harm according to standards applicable to their abilities, experiences, and lifestyle as measured against other members of the community;
- People have received and continue to receive information, training, and education designed to maximize their personal safety and membership in the community and neighborhood of their choice;
- People are provided with all relevant information necessary to make an informed decision. The information is provided in a language and manner that is most understandable. Substitute decision-making is available and utilized whenever there are concerns around the person's capacity to make informed decisions, not as a substitute for the person's choice, however, but to augment the likelihood that all consequences are known and acceptable;
- People receive the health and related services they need;
- People are treated in a respectful manner and those who support people with developmental disabilities are viewed with equally respectful attitudes. This includes clearly defined parameters to the relationships that developed between a person with a developmental disability and the support worker. The boundaries should address issues such as friendship versus employer/employee, use of personal property and possessions, and any limits to supports that are available;
- If abuse, neglect, or exploitation is detected investigations are conducted in a timely manner.

- Acceptable expenditures when public funds are used are clearly defined prior to any allocation or expense being incurred;
- In the everyday pattern of life there are requirements that are non-negotiable. In the implementation of consumer-directed services there are system requirements and expectations that are also non-negotiable. These must be identified and, whenever possible, mutually agreeable outcomes and measures should be developed. It is critical to define and articulate the level of risk that the system is willing to assume in the implementation of consumer-directed services; and
- Concomitantly, there are system requirements and expectations that are flexible and/or tied to existing service delivery models of supports.

Consumer-Directed Model Intermediary Service Organization (ISO)

The use of public funds raises a number of key questions that must be addressed, at least in part, prior to any implementation of any model for consumer-directed services. The key issues that must be addressed relate to program and fiscal accountability, compliance with existing regulations, and statutes and liability for negligence affecting people with developmental disabilities. Therefore, discussions around consumer-directed services often include the development of an intermediary service organization often referred to as an ISO. Such models are relatively common in systems supporting people with physical disabilities. Nonetheless, an IS0 can often be the bridge that allows for balance among competing goals of providing services that comports with consumer choice and control while also ensuring a certain degree of fiscal accountability and compliance to various regulations, to the IRS in particular.

A key decision facing state policymakers in addressing the IS0 model often centers on the scope of services offered. A fiscal intermediary can be limited to compliance with state and federal withholdings or become a broader IS0 and offer other support services. There is no single set of services that an IS0 must provide. Rather, state policymakers should establish the scope such that the duties and responsibilities of an IS0 comport with the desired system change outcomes that are envisioned. Additionally, an IS0 can be an independent entity, that is, it is an autonomous entity with a scope that is exclusive to consumer-directed services or it can become a specific function offered by the existing service providers' network.
The absence of an IS0 should not prevent piloting various aspects of consumer-directed services. However, once the pilot is completed, any statewide rollout of the model must include a mechanism that will ensure the following:

- Compliance with applicable Federal tax and labor laws;
- A means to address liability for negligence, theft, exploitation, or harm;
- A means to ensure timely and appropriate payment for services;
- A means to help comply with state regulations and rules; and
- Who is the employer of record? Are service attendants independent contractors? Are they employees of the consumer? Are they employees of the ISO? Are they employees of a service provider?

The work of Susan Flanagan, MedStat, identifies six IS0 models in her presentation to the Arizona Association of Programs for People with Developmental Disabilities (Tucson Arizona, April 2000). Her models follow:

TABLE 4: Models of Intermediate Service Organizations

ISO Model	Operating Entity	Worker's Employer Of Record	ISO's Responsibility
Fiscal Conduit	Government or Vendor	Individual or representative, unless they choose to use an agency for the provision of supports	Disburse public funds via cash or voucher payments to individuals/representatives and related duties, such as invoicing the state and processing time sheets
Government (IRS Employer Agent) Fiscal IS0	State/County	Individual or representative, unless they choose to use an agency for the provision of supports	Acts as the "employer agents" for individuals/representatives for limited purposes of withholding, filing, and depositing federal employment taxes. Also invoice the state for public funds, manage payroll, and distributes workers checks and pays other vendors, as required. Can also deal with worker's compensation and other insurance policies on behalf of the individuals/representatives
Vendor Fiscal IS0	Vendor	Individual or representative, unless they choose to use an agency for the provision of supports	Same as Government model except that the Vendor performs the fiscal intermediary requirements outlined by the IRS
Supportive IS0	Distinct vendor, services provided through other IS0 models or independent individuals selected by an individual or state	Individual or representative, unless they choose to use an agency for the provision of supports	Provide an array of supportive services to individuals, representatives, and on a limited basis, to workers, including such areas as employer skills training, tax and payroll management, and assist in the recruitment and hiring of regular and relief staff
Agency with Choice IS0	Agency	Agency or any subcontractor to that agency	Invoice the state for public funds, process employment documents and criminal background checks when needed or required, and manages all aspects of payroll on behalf of the individuals/representatives. May also provide other support services, including training of staff and monitoring performance
Spectrum IS0	Agency	Individual, representative, or agency	Umbrella network relying on subcontractors or the individuals and performs fiscal conduit, fiscal agent, and supportive services

The selection of a particular model is related to the degree of ability and the level of control and involvement desired by the person with developmental disabilities. If the ability and desire are low, than an *Agency with Choice ISO* that offers various levels of participant direction and supportive intermediary services is the preferred option. Conversely, if the ability and desire were high, than *a Fiscal Conduit ISO or Supportive_ISO* would be the model of choice.

IV. Findings

Provider Findings

The Commonwealth currently has over 75 SCL certified providers, and is actively working to certify an additional 25 providers. For this study, Mercer conducted site visits and policy reviews of twenty-five (25) agencies selected at random and approved by the Division of Long Term Care. The sample of providers included representative agencies from metropolitan and rural areas, large and small agencies, and existing and start-up agencies. A list of surveyed agencies and summary data from each of the providers sampled are included in the Attachments.

In conducting the readiness reviews, Mercer staff tested for evidence of self-determination management components previously listed. In addition, Mercer staff examined the following provider policies and practices:

- The availability of a management structure and leadership to support self-determination;
- The presence of an identifiable mission, vision, philosophy, and/or business plan to support self-determination;
- The existence of policies, procedures, and training that can support self-determination implementation;
- The presence of consumer planning and budgeting activities that could support self-determination;
- Marketing activities that already exist, or could be modified to promote self-determination;
- Membership in community organizations that could support self-determination-related activities; and
- Financial and management stability.

From these visits and interviews, the Mercer team respectfully offers the following findings:

Finding #1—SCL programs appeared well-organized and managed

The review process comprised several activities including 1) A review of policies and procedures; 2) Staff qualifications and training; 3) Staff turnover; 4) Internal and external communication protocols; 5) Direct observation and interaction of staff and consumers; 6) Review of management protocols, and; 7) Limited review of records. Review team members were experienced directors/managers of large agencies supporting people with developmental disabilities.

Site reviews of the agencies surveyed found that they were well organized and managed. Direct care staff were trained and quality interactions with consumers were observed in all settings. Direct care staff turnover was reported to range from 10 percent in rural areas to 30 percent in urban areas; turnover experience in other states ranges from 30 percent to 70 percent. Staff ratios of 1:3 people were observed in 23 of 25 settings. In two observed instances of acute need, 1:1 staff ratios were present. A review of staff restraint and psychotropic medications policies found that policies and reported practices were consistent with CMS HCBS look-behind published

guidelines (August 2000). All agency policies and procedures were current and interviewed staff were knowledgeable of individual service plans.

Finding #2-Existing agencies have the capacity to understand, develop and implement consumer-directed services

Mercer site reviewers found a foundation for self-determination within the service provider network. Specifically, the review discovered good internal organizational control that would support the managerial and fiscal shift to more individualized services for people with developmental disabilities. The service provider network is grounded in personal values and principles that are consistent with self-determination. Most agencies supported people in residential settings of four beds or less; Mercer reviewers considered these settings to be of a manageable size. All providers were experienced in developing community inclusion opportunities. Agencies with experience in providing family support, individual support, and respite were best prepared to pilot consumer-directed services.

Prior to the implementation of any pilot on self-determination it is imperative for participating agencies to have an in-depth knowledge of Medicaid and the ability to effectively interface with the Medicaid agency. It is also essential that consumers, families, service provider staff and agency personnel have a common understanding of self-directed services and understand their role and responsibility.

Finding #3—State program monitoring was effective and integrated into agency management activities

Program monitoring conducted by DMR was seen as valuable and findings were considered accurate by the provider agencies surveyed. Agency staff were familiar with state monitoring standards; agency directors presented current plans of correction. Agency directors described the state monitors as competent and fair; additional technical assistance was identified as a need, especially in dealing with people with significant behavioral health, sexual predation, and/or community intrusion issues. Incident and accident monitoring is occurring consistently and effectively. Trends and patterns analysis is routinely conducted, and issue resolution is tracked to completion.

Finding #4—Providers noted positive to excellent working relationships with the Division of Long Term Care and the Division of Mental Retardation

Agency directors reported that their working relationships with the state Medicaid and Mental Retardation agencies was positive. Specifically, providers noted that state staff were responsive and timely in resolving issues and questions. Also, agency directors noted that both state agencies appeared to have a common vision and program expectations. The state/provider relationship was described as greatly improved over the past four years. Select providers, however, continued to express concern regarding previous state efforts to implement managed care.

Finding #5—Current service configuration influences the ease to transition to self-directed services

Agencies that focus on apartment living and supported employment and/or competitive employment services to the people they supported tend to have less managerial challenges converting to self-directed services..

Finding W-Direct care staff compensation appears to be low, but staff turnover appears to be stable

Agency directors indicated that direct care staff levels were stable and vacancy levels were below 30 percent/year. Direct care compensation, however, was reportedly $6.25/hour to $9.00/hour for entry level staff. By comparison, Mercer compensation data (attached) for competing Commonwealth employers shows that developmental disabilities providers are not competitive with other health care/long term care industries ($18.10/hour.), retail ($8.91/hour.), food service ($9.24/hour.), or janitorial services ($9.47/hour.). Retention of direct care staff, particularly in rural communities, appears to be high, suggesting that workers remain for other reasons than compensation. A number of the provider agencies interviewed report excellent benefit packages, including health, dental, life, 401K, profit sharing, and bonus plans simply to obtain the staff that are currently employed by the agency. One provider agency reported that their direct care worker is making $13,000 per year and the support coordinator is making $20,000 per year. These compensation plans do not afford a working family wage and are below the current low-income standards.

Finding ##7-The impact of person-centered manning (PCP) on individuals' lives is widely varied

The Commonwealth has progressed further than most other states in implementing Person Centered Planning in SCL programs. All provider agencies sampled are currently conducting PCP. However, 70 percent of the provider agencies did not follow the PCP, but rather treated the process as a DMR program-monitoring requirement. The primary barrier with the PCP is that the assignment of funds and choice of services are not clearly connected to the plan. Provider agencies remain committed to the use of the person-centered process emphasized by DMR, and are able to implement such plans in the Family Support program. A number of the providers are currently servicing individuals in this program and see this program to be a possible platform on which to build the current system.

Finding #&Choice of Services is limited. narticularlv in rural settings

During the interviews, two concerns were raised about the personal choice of providers and services. The first concern is that the current SCL Waiver recipients are only allowed to choose from the certified list of SCL Waiver providers that are approved by the state system. Agency directors felt that this limitation would present a barrier in providing services and supports from non-traditional agencies and community resources. Secondly, selected providers acknowledged that consumer-directed services would impact the overall industry competitiveness between the providers. Because the current support coordination program allows providers to control what is being offered, consumer-directed would eliminate that relationship.

Operations Findings

Transferring control of resources from the government to individuals and their families requires specific financial systems that differ from those traditionally used in systems of care for developmentally disabled individuals. Mercer evaluated the operating and financial systems present in the Commonwealth as to their readiness to implement a self-determined model of care. Because the fundamental shift in self-determination is predicated on the assignment and control of resources, the financial systems become a critical component of a successful implementation. Mercer performed a financial review of the various data sources and the methodology used to set rates for the SCL waiver program. This section of the report describes:

- what data sources Mercer reviewed and our observations,
- Mercer's understanding of how the data are currently used,
- rate-setting issues under SLC and potential issues in a self-determination model, and
- other issues for consideration when moving to a self-determination model of care.

Mercer staff has reviewed several data sources in addition to correspondence between the Commonwealth and SCL Waiver providers regarding finances and rates, the SCL manual, the SCL waiver amendment (effective 9/1/00), and documentation on the rate methodologies. Mercer used this information to compile comments throughout this report. Mercer analyzed different data sources in order to determine how providers are reimbursed now in the SCL waiver and what changes may be anticipated if the Commonwealth chooses to proceed with a model of self-determination. Appendix E contains a worksheet that compares the unit cost per service of each of these data sources, and bar charts illustrating the distribution of providers by average per capita cost. Appendix E also includes a list of the data sources reviewed by the Mercer fiscal staff.

Finding #1—Independent support coordination is needed

Mercer staff observed exceptional agency support coordinators who were knowledgeable and active in supporting people with disabilities. However, the current system creates an inherent conflict of interest when the support coordinator is employed by the service provider. This conflict is evidenced in the review of PCPs. All SCL providers interviewed reported that consumers were limited to services offered by the support coordinator's agency; in limited instances, providers reported that individuals were directed to services other than those outlined in the PCP because that was "what the agency was offering".

Finding #2-Fiscal intermediary service is needed

Individual fiscal management is not clearly understood or accepted by the provider agencies. While agency financial management systems were in place and operational when managing state allocations and contracts, agency directors expressed significant concern about placing purchasing control with the individual. None of the agency directors interviewed had direct experience with fiscal intermediary services where individual assets reside with an independent financial institution. In most programs, individual funding is blended at the agency level and is not directly related to the type or amount of direct care support received.

Finding #3-Individual use of SCL services has significantly increased and people are receiving a majority of the services offered by their provider

Similar to the finding on independent support coordination, people are assigned increasingly more SCL services than previous years. This trend is consistent with new, as well as current, SCL enrollees. The observed use gives the appearance of over-utilization of services. A service utilization review by an independent agency needs to be present to ensure that people are receiving the level and amount of service they need.

Finding #4—SCL rates need to be recalculated based upon a consistent rate methodology across all SCL services

The historical basis for the current SCL rates has changed and an updated methodology needs to be provided. There is no current standardization nor are the rates portable between service categories.

Finding H-Additional data are needed to analyze the impact of self-determination

The Commonwealth has a good financial database for tracking provider capacity and expenditures. In order to accommodate self-determination, the Commonwealth should consider developing added data to analyze the impact of pilot initiatives.

- Provider Disruption – Because people will make different choices under self-determination than under the current SCL program, Medicaid will need to monitor the effect on providers with regard to the type and volume of services. This will allow the Commonwealth to make generalizations as to how the current providers might be impacted by a self-determination model.
- Direct Care – The cornerstone to any HCBS program is the direct care staff worker. The Commonwealth will need to monitor the salaries and benefits needed to attract and retain these workers to ensure the system has capacity to serve its clients.
- Individual Choice – The Commonwealth should monitor the changes individuals make in terms of their service provision. This includes the type of services they choose, volume of services they use, and the provider they choose. This will allow the Commonwealth to make generalizations as to how the entire system might be impacted by a self-determination model.
- Budget Impact – The Commonwealth will need to closely monitor the self-determination pilot to estimate the possible financial impact of implementing the program statewide.
- Rural Impact – One of the advantages of using a self-determination model is that individuals who previously could not obtain services due to being in a rural or remote location, can find creative ways to use their funding to meet their needs. The Commonwealth should monitor self-determination to see if it improves access. And coupled with the analysis of the direct

care data, it can determine what rate changes might be necessary for clients in rural and remote locations.

- Service Change – Over time, individuals will make changes in their service packages. These include both long-term changes, such as revising their PCP, and short term changes, such as a broken leg. The Commonwealth needs to monitor these changes to understand the impact on providers and the budget.

Consumer Findings

In completing the consumer portion of the assessment process, the Center for Outcome Analysis developed a survey instrument that was sent to the Division of Long Term Care for approval prior to distributing to the consumers receiving services under the HCBS Waiver. Once distributed, Mercer received approximately a 40 percent return from the consumers and their family. The results of the surveys have been tabulated and are provided in the tables that follow this introduction. Also, the Division of Long Term Care provided a list of selected individuals to Mercer in order to arrange personal interviews either in their home environment, in their day treatment program, or in a community setting. The findings from the interviews are also provided.

Consumer Survey Findings

Finding #1—How did people describe their living situations?

The types of living situations listed by the respondents were quite varied, as shown in the following table:

Living Situation	Percentage of Respondents
With Relatives	**13 percent**
Group Home	**15 percent**
Foster Home	3 percent
Supported Community Living	53 percent
Independent Living	1 percent
Other	15 percent

Finding #2—How many people live with you?

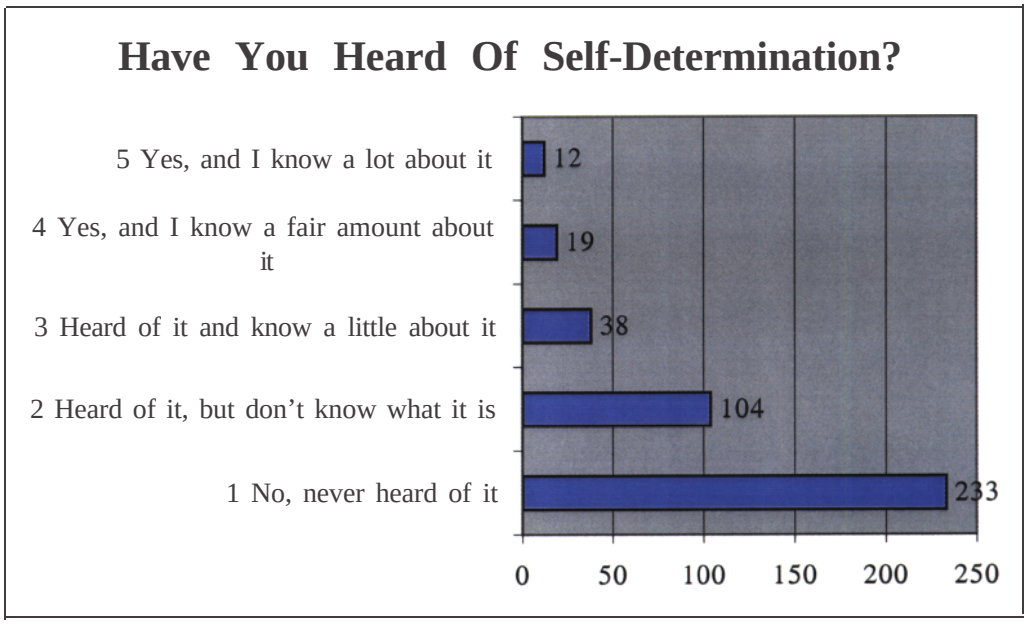
The average was 2.0. Again, there was considerable variation as reflected in the following table.

Number of Other People Per Home	Number of Respondents
Living alone	10
One person per home	70
Two people per home	244
Three people per home	45
Four people per home	26
Five people per home	9
Six people per home	3
Seven or more people per home	7

Most of the respondents' (244) lived with two other people. A few lived in large settings with seven or more. The emerging standards for congregate living continue a pattern where large settings are being replaced with smaller environments. It is widely held that the smaller the setting, the more individualized services and supports become. The more individualized services and supports are the higher the consumer ratings are around satisfaction. The fact that a majority of people surveyed are living in smaller settings is a highly positive indicator.

Finding #3—Do people know about self-determination?

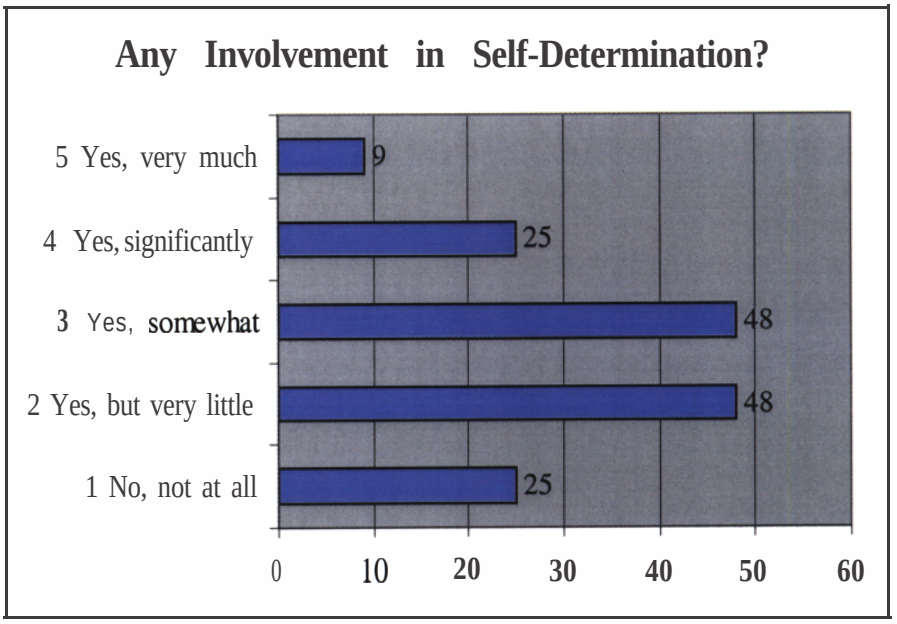
Very few people responding to the survey had knowledge of self-determination as demonstrated by the following chart



This graph showed that information about self-determination had not in most cases reached these waiver service recipients. Only 69 people (17 percent) had heard of self-determination and said they knew anything about it. Another 104 (26 percent) said they had heard of self-determination but knew nothing about it. Information about self-determination and or consumer-directed services is a critical component for the implementation to be successful. The response rate for the Commonwealth is not uncommon. Rather the survey results reveal the importance of planning and information strategies as the first step in moving forward. For those reasons, the first step in the self-determination pilot effort will have to involve publicity, training, seminars, conferences, brochures, and any other means the Commonwealth might select to inform people. The target audiences should include in addition to consumers and their families, service providers, agency personnel and staff responsible for monitoring and regulation compliance.

Finding #4—For people who do have knowledge of self-determination, how involved are people in managing their own supports and care?

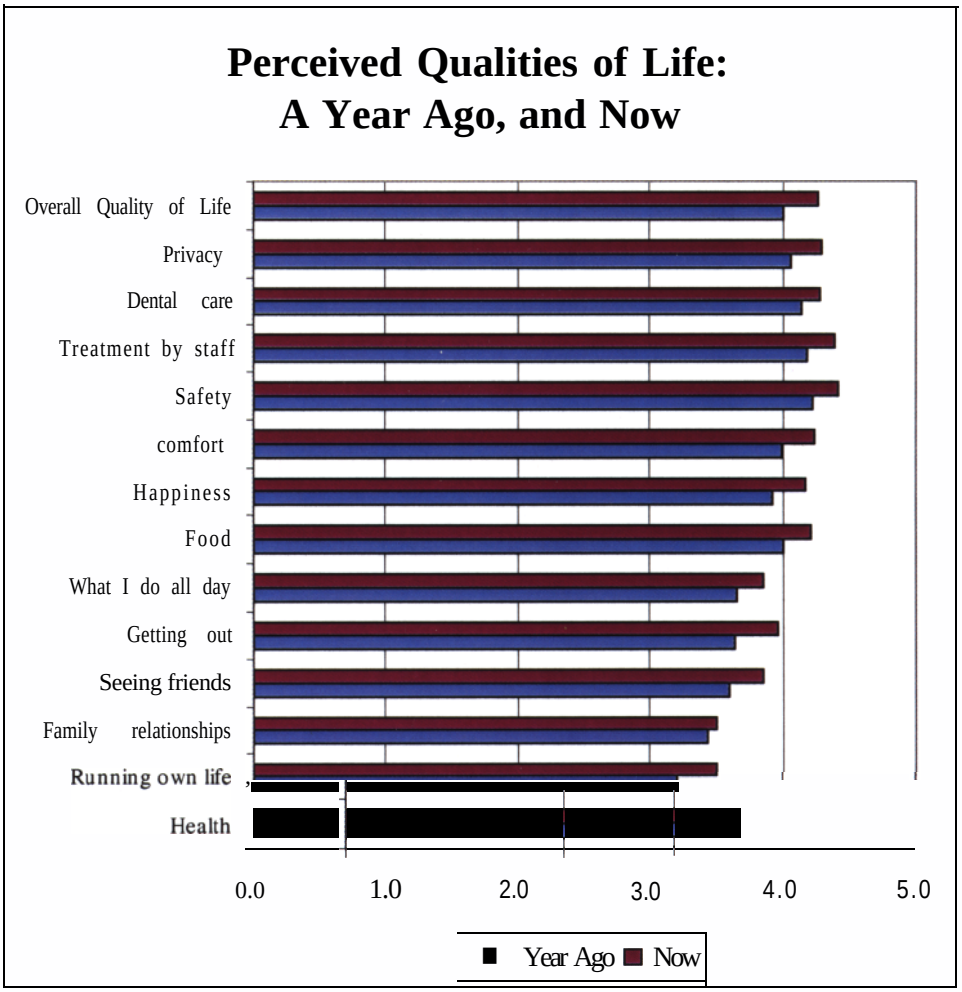
In this analysis, people who had said they'd never heard of self-determination were not included. Leadership on consumer-directed services has been developing slowly in most states, and the survey reveals the same pattern for the Commonwealth. There has not been widespread involvement thus far, something that will change when the systematic statewide initiatives begin. The responses came in as shown in the following figure.



Finding # 5—Do people have a better quality of life today than one year ago?

In order to learn what the waiver participants thought about the qualities of their lives, we applied COA's "Quality of Life Changes" scale. Basically, the instrument asks people to rate 14 areas of life quality on 5-point scales, for "A Year Ago" and "Now." (See Attachments for the complete format and content of the scale.) The darker bars show the average responses for "Now," and the lighter bars show the average responses for "A Year Ago." In every one of the 14 areas, people (and/or the surrogates who knew the people best) believed they were better off

when they completed the survey than they had been a year before. COA ran statistical tests on these perceived changes, and every one of them was statistically significant, and 13 of the 14 were highly significant, meaning that the odds that such a change occurred by chance were less than 1 in 10,000.The results were as shown in the graph following.



The largest areas of perceived change were in Getting Out, Running My Own Life, Seeing Friends, Overall Quality of Life, and Happiness. These are certainly encouraging findings. It is true that the magnitude of the perceived improvements was rather small compared to the pre-test data. But it is very positive to see that the Waiver recipients, and those closest to them, believe their lives have been "getting better" over the past year.

Finding #6—What things do people value most?

The survey asked people to indicate what things were most important to them. From a list of 30 quality of life dimensions, developed from thousands of individual visits and surveys over the years, respondents wrote a "1" next to the most important thing, and a "2" by the second most important thing, and so on down to "5" for the fifth most important thing. During analysis, we first calculated how many people put each item in their "top 5," and then gave the greatest "weight" to items marked with a "1" (for Most Important). In this way, we calculated the weighted sum for each item. In the following table, the Weighted Sum shows this computation.

What's Important to You: Values in Rank Order

Quality of Life Dimension	Weighted Sum
Love	467
Family-like atmosphere	419
Comfort	315
Earn money	311
Home-like place	310
Friends	290
Health	269
Choicemaking	265
Dignity, respect	246
Safety	225
Permanence of home	220
Working for pay	201
Stability	182
Freedom from abuse	161
Communication	135
Medical attention	133
Being kept busy important to you	120
Travel, vacations	115
Productive day activities	106
Girlfriends/Boyfriends	93
Religion, worship	77
Being with other people with disabilities	72
Assistive devices important to you	65
Self-care skill development	62
Supports for problematic behavior	54
Integration, inclusion	54
Development, learning	42
Community acceptance	40
Exercise, fitness	27
Self-esteem	25
Monitoring the quality of services	18
Self-determination	15
Large facility to live in	0

People in the Kentucky Waiver program expressed "Love" as their highest value. Having a "Family-Like Atmosphere" followed this. The next three were "Comfort," "Earn Money," and "Home-Like Place." Looking at the top and the bottom of the table is very informative. At the top of consumers' priorities are things that are universal to all citizens, the simple fundamentals that traditional human service systems have not addressed. At the bottom are the goals that professionals have tended to espouse more often, such as self-care skills, integration, monitoring, having a large facility to live in (which received not one rating). These findings are highly compatible with consumer-directed services.

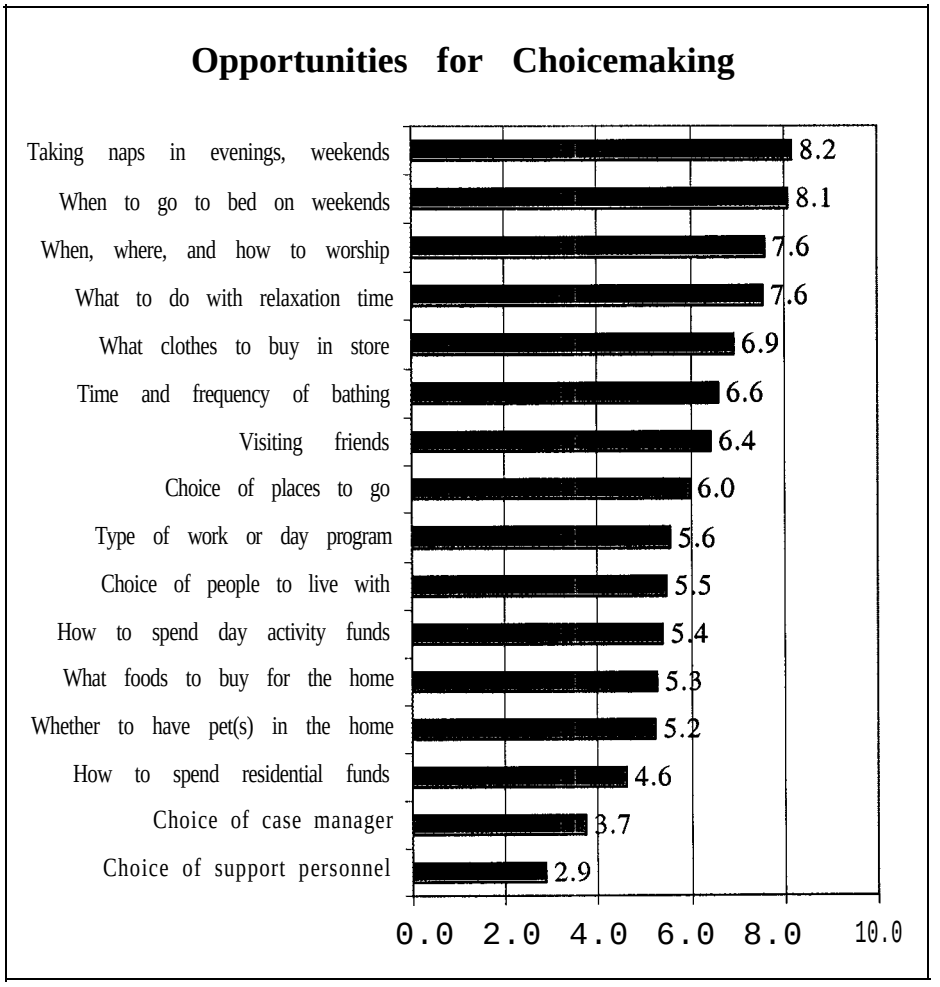
The rating of self-determination as being next to last may be more a reflection of a lack of understanding than a statement of disinterest. The highest rated items are outcomes directly associated with self-directed services and these findings are consistent with Mercer's experience elsewhere.

Finding #7—To what extent do people make decisions about their care and support?

The Decision Control Inventory measures the extent to which people and their allies make decisions in big and small matters, versus having those decisions made by paid professionals. This scale tends to be particularly informative when applied before and during self-determination. Here, we have only collected it once, and cannot see pre-post changes. Nevertheless, the items in the scale can be rank ordered to see what areas of life people have the most and the least control over.

This group of supported living Waiver recipients had their highest degree of power and control over "the little things" in their lives: taking naps, weekend bedtime, worship, free time, clothes to buy. They had the least power over "the big things" such as choice of staff, choice of case manager, and how to spend residential dollars. These "big things" are precisely what self-determination is designed to change.

If self-determination is implemented for some or all of these people, then we will be able to detect its impacts on power and control with this scale. The participants would be expected to increase their control over some of the "big issues" at the bottom of the graph, just as they have in a number of other states. The following graph shows the results.



Finding # S-How many people are involved in the individual planning process?

The individualized planning process is more highly developed in the developmental disabilities field than in any other human service. To get a glimpse of how planning has been done for people with developmental disabilities; we asked how many people were involved in each person's planning process. The answers were quite varied, as shown in the table below.

Size of the planning group	How many people had this size planning group?
1	4
2	8
3	18
4	42
5	88
6	75
7	33
8	21
9	18
10	13
11	3
12	4
20	1
Total	330
Item Left Blank	111
Grand Total	439

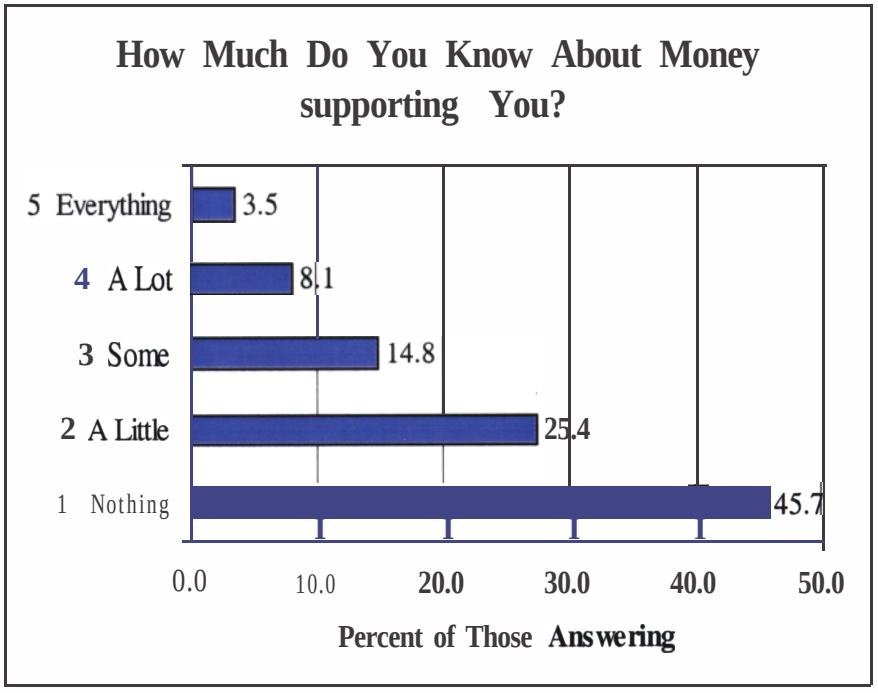
This table shows that 4 people said they had a planning group of size 1, 8 people said their planning group had two members, and so on. The most common size of a planning group was 5, with 88 people reporting that size. Another 111 people left this item blank. The average size of a planning group was 5.8 members. We also asked how many planning group members were paid, and how many were unpaid. The averages were:

Average Group Size	Average # Paid	Average # Unpaid
5.8	4.2	1.6

As in most existing service systems, the planning process for people with developmental disabilities is tilted toward paid team members, often called "professionals." Paid members of planning teams outnumber the unpaid members by almost 3 to 1. Self-determination and or consumer-directed services is highly compatible with a planning process referred to as Person Centered Planning. Person Centered Planning relies on a person's circle of friends to aid in the outline that services as the individual's plan. Paid staff are highly important members of the team; it is often the involvement of friends that enriches the plan with a direction that has meaning to the person with developmental disabilities. This provides another criterion for future measurement of self-determination impacts. The involvement of unpaid allies in the individual planning process is expected to rise during self-determination.

Finding #9—How much do people know about the public funds that are being spent for personal supports?

One of the odd things about traditional service delivery in our country has been that people with developmental disabilities and their families often have no idea how much their services and supports cost. In general, staff do not either. This is a significant issue for numerous reasons. For the purpose of this report it is significant that people lack information about the cost of their services. A total of 403 of the 439 respondents answered this question. The responses are presented graphically in the next figure.



Nearly half of the respondents said they knew nothing about the public funds being spent on their behalf. Only 3.5 percent said they knew everything about their support funds. As in most service systems, people with developmental disabilities are not well informed about the money issues.

We also asked people who knew a lot about the money issue, how much was the total dollar amount. Only 21 people responded, and their mean average response was about $28,000 if we use the mean, and $12,000 if we use the median. (A few people reported very high costs, which affects the mean a great deal, but does not affect the median. The median is probably the better measure in this case.) Since self-determination is inextricably intertwined with awareness of, and control of, individual budgets, this is an important finding. Participants and their allies, along with paid staff, will have to find out what's currently being spent, and how it's being spent, in order to move forward in self-determination.

Finding #10—What are other comments?

In every survey, we asked, " Please write any comments you have about Supported Community Living in the Commonwealth or about Self-Determination, if you want to." Responses to these questions were varied and rich. The responses can be broken down into a number of different categories for this question.

- Individuals not agreeing with the SCL Waiver Program and the services that are being received.
- Individuals that have benefited from the program and have encouraged the expansion of the program including the services.
- Individuals that did not understand the concept of Self-Determination and how it would impact their life. In many responses, these individuals preferred to receive more information on the concept.
- Individuals that were unable to comment or expand their understanding due to their limitations.
- Individuals with no response.

The majority of the individuals that responded to this question fit into the second bullet above and strongly supported the program. They were supportive of the program because it allowed them more freedom in their living situation, more choice in their daily activities, the people that they wanted to spend their time with, and the opportunity to develop stronger living skills.

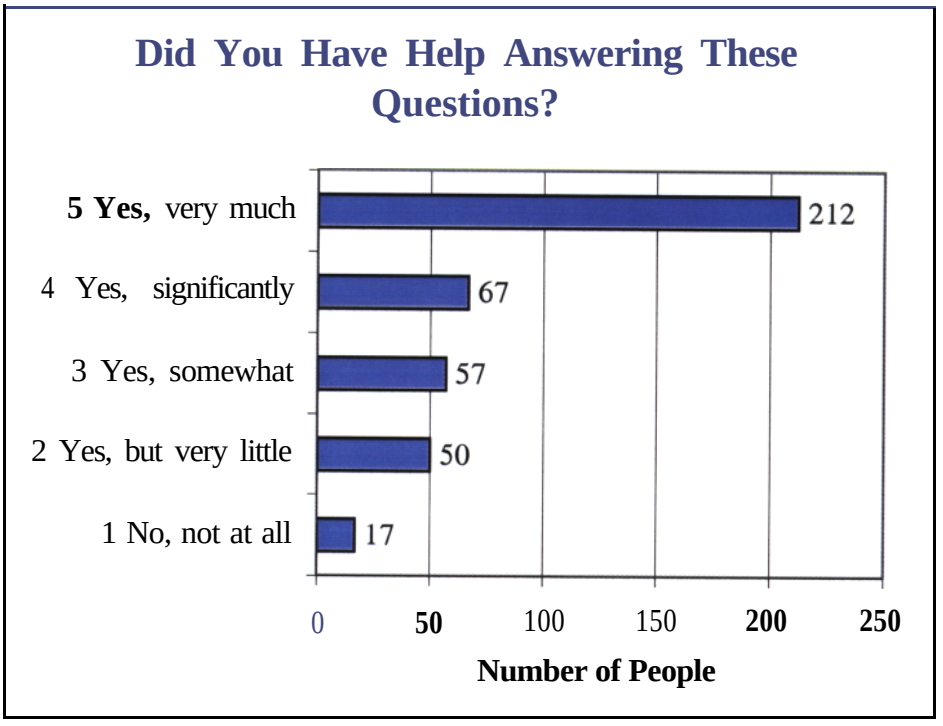
The individuals that did not support the SCL Waiver program indicated their frustrations with the rules, the confusion of policies, the rates, and the overall service delivery system and the lack of enough services being available.

Finding #11-What would YOU change?

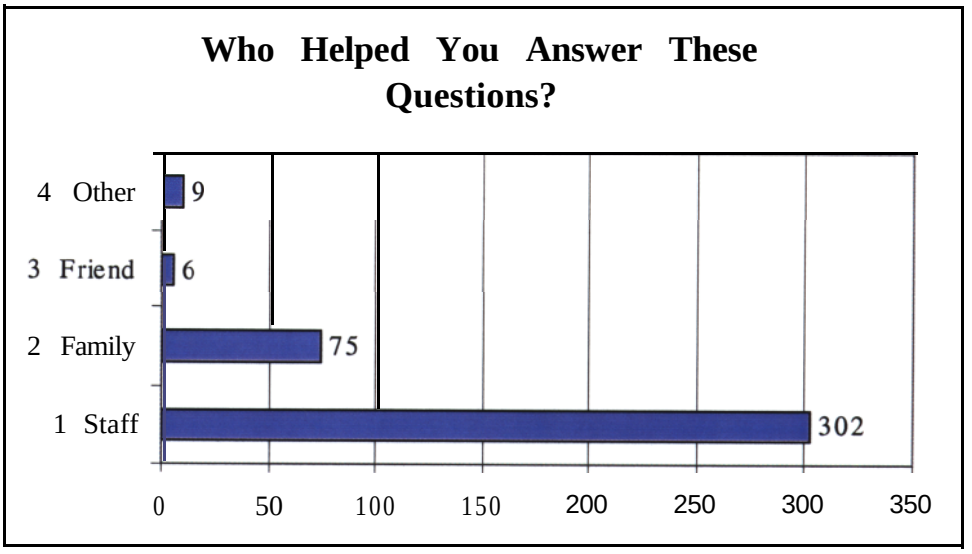
Many of the responses centered around "the little things" rather then "the big things" as discussed earlier. In regards to wanting more choice in "the big things" a number of the responses centered around being able to spend more time with certain individuals including friends and family members, being able to control their spending options, living under certain conditions, and employment opportunities. "The little things" centered around immediate fixes such as wanting more candy, ice cream, and simple life pleasures.

Finding #12—Did people receive help responding to the survey

We asked each person, "Did you have help answering these questions?" Most people did have a lot of help, as shown in the following graph.



For those who had help, we asked, "Who helped?" The result was that it was almost always staff or family members, as shown below,



This is also not unusual. However this finding does raise one area of caution. The answers are often filtered through staff or family member's perceptions and opinions. This in of itself does not present problems; rather additional efforts should be taken during any pilots to seek information on people's preferences. We must try with all diligence to communicate directly with the person, and only when necessary, accept the assistance of a surrogate. On the other hand, we must not reject these finding or regard them as not valid. They are simply the best that we know how to obtain for people with cognitive disabilities.

Consumer Interviews - Findings

In addition to the consumer surveys mailed to 1,500 people and people interviewed during program site visits, Mercer staff also personally interviewed seven people in their communities who were receiving SCL services. These individuals were selected by DMR and represented a variety of personal situations and circumstances. The purpose of the interviews was to explore the interest and perceived value of self-directed services with specific individuals, and to test the amount of involvement and personal risk which people were willing to assume. Individuals who were selected were considered to be examples of candidates for the self-determination pilots. There was no attempt to select people randomly, but rather focus on more specific implementation and personal control issues. Characteristics of the seven people who were interviewed included the following:

- People resided in Morehead, Williamsburg, London, Louisville, and Lexington
- All people were of adult age
- All people had person-centered plans and active support coordinators
- Two people were living in their own homes or in parent homes; five people were living in subsidized living situations
- Six people were actively engaged in day programs which included employment and/or community inclusion activities; one person was not involved in a formal day program, but was engaged in activities organized by parents
- Four people were supported by community mental health/mental retardation boards; three people were supported by new SCL providers

Key findings are as follow:

Finding #l-Overall, people were satisfied

Individuals were generally pleased with the overall services that they were receiving. Even so, five of the seven people expressed a high interest in changing one or more conditions in their lives. The following table summarized those areas that would be impacted by self-determination:

Individual	Age range	Gender	Living Situation	Day Situation	Areas of Self-Determination Impact
Person #1	35-40	Woman	Parents/own home with in-home support from CMHC	CMHC – work program	Interested in sustaining current in-home support staff; decrease use of CMHC day program and increase community inclusion (recreation) opportunities
Person #2	50-55	Man	CMHC – staffed residence	CMHC – vocational program	Interested in moving to own home with fewer people; enjoyed current day program and friends with no interest in changing
Person #3	50-55	Woman	SCL – staffed residence	SCL – work program	Interested in sustaining current situation; active in hiring personal care staff
Person #4	50-55	Woman	CMHC – staffed residence	CMHC – community inclusion	Interested in obtaining supports from other providers/non-traditional providers
Person #5	25-30	Man	Parents/own home with in-home support	Program provided by family	Interest in maintaining personal control and customizing day and home supports; limited interest in using existing SCL provider network
Person #6	21-25	Man	SCL – staffed residence	SCL – individual support	High degree of satisfaction with current program; interested in ensuring that current situation is sustained
Person #7	50-55	Woman	CMHC – staffed residence	CMHC – community inclusion; part-time work	Interest in reducing structured day program activities and having more personal time

Finding #2—No individual managed his/her own public funds:

No individual had an individual/family budget which included public funds, nor were people aware of the amount of public funds (e.g. DMR, MAA) allocated to their services. All people did have personal financial accounts, which included work compensation and clothing/personal/incidental funds. All people had financial stewards who assisted them with the expenditure of personal funds.

Finding #3-Most people felt they had choice and input into the selection of their residential support direct care staff:

All people and/or their families described personal involvement in the hiring decision for their personal care staff. This involvement included both staffed residences and in-home personal support workers. With the exception of the individual whose family was directly organizing day activities, no individual described significant involvement in the hiring decision for day program staff.

Finding #4—No one wanted to change everything:

While five of seven people wanted to change some aspect of their current support, no one wanted to make extensive changes. For example, no one expressed an interest in moving to a different community or changing providers. Instead, people described their desire to maintain current valued staff and community relationships, and to increase their opportunities to actively participate in their communities. Of significance to four people was the desire to assure that valued personal care staff could be retained and not leave for higher paying work.

Finding #5—People who were older wanted to work less:

Employment did surface as a key area for three people individuals who were over the age of 50 years. Specifically, these people did not enjoy their jobs and expressed a desire to reduce their work time. Each felt little personal control or influence over that decision and stated that they had few opportunities to explore non-work options.

Finding #6-People who were supported in new SCL programs felt they had more personal control than people who were supported in CMHC programs:

Three of seven people described a concern that their choices were limited to the supports and services offered by the CMHC. These three people described situations where they felt required to participate in all services offered regardless of their personal interests. People supported by the newer and smaller SCL programs described more personal control than those supported in CMHC programs.

Overall, individuals believed that to some degree they felt as if they were living under some degree of self-determination now. Individuals appeared to be living enjoyable lives and described the opportunity to make more choices currently than in the past. The interviews revealed that overall people with developmental disabilities were pleased with the overall services that they were receiving. The interviews also confirmed that there are components of consumer-directed services currently within the system of supports for people with developmental disabilities.

The interviews also reinforced a finding experienced in other states. That is most people would make, at least initially, very few changes with services and how those services were provided if those options were presented to them under a consumer-directed model.
Consistent with Mercer's findings in other states, the majority of choices and decision-making activities are being made on issues that are important for quality of life but of lesser urgency. These decisions tend to be around what to eat, what to wear and how to handle at least portions of one's free time, rather than changing provider or support staff.

V. Recommendations and Next Steps

The Commonwealth is well organized and positioned to implement self-determination with the exception of one major issue. The need for independent support coordination and an aggressive and independent utilization management system is critical. Without such controls, the State is exposed to increased cost overruns and over utilization of services. Respectfully, Mercer recommends the following actions:

1. **Independent Support Coordination:** Establish an independent support coordination service that provides consumer assistance with person-centered planning, and obtaining and negotiating service delivery.

2. **Independent Utilization Review:** Establish a utilization review process that is based upon quality of life and quality of care outcomes. Pre- and post- consumer satisfaction and outcome surveys should be conducted to test for impact.

3. **Target Fiscal Intermediary Services:** Test alternative forms of Fiscal Intermediary Services to determine the methods and risk of decentralized individual financial management.

4. **Small Decentralized Pilots:** Pilot initiatives with a focus on small group implementation reflective of the geographic diversity of Kentucky should be undertaken. The consumer surveys support a conclusion that implementation should be deliberate with clear outcomes identified for evaluating the effectiveness of the pilots. The pilots could focus on new people leaving the public education system and wishing to enroll in SCL services. Additionally, the pilot could also focus on people currently receiving services under SCL but who wish to change their current supports.

5. **RFP Pilot Providers:** Providers wishing to participate in the pilots should be selected through an RFP process.

6. **Flexible Rates and New SCL Service Definition:** A standardized rate schedule should be developed for individuals choosing to participate and the SNAP assessment tool suspended for pilot participants. The current SCL waiver should be amended to include a self-directed service definition and quality assurance criteria.

7. **Contract for Data Collection:** Secure a contract with an organization to collect and review pilot findings, develop baseline data and comparative analyses, and conduct simulation modeling.

The recommendation is to structure the pilot in a manner that allows for a phased introduction to system change associated with self-directed services. There are two components that are recommended to be included in the pilot: development of individual budgets and impact on service providers. Development of individualized budgets focuses on how budgets for self-directed services are developed, implemented and monitored.

The second component examines the impact on the service providers as the revenue flow alters from capacity contracts to fee-based. The latter aspect of self-directed supports is critical and reflects one of several paradoxes. That is, there needs to be capacity in order for people to have choices and options and there needs to be a certain degree of predictability to maintain capacity. For these reasons, it is strongly recommended that two pilots be constructed and implemented to run simultaneously. After the pilot has been completed, there is a need for one additional area of consideration. This area centers on fixed costs affiliated with group homes and other congregate settings. A review of strategies to convert to a consumer-directed and controlled budget model must include planning on how to address fixed costs.

Individualized Budgets:

Step 1: Define the parameters

The first set of decisions is to determine the number of participants that will be enrolled in the pilot. The two options for consideration are to either select a number of people or establish a maximum dollar value. Usually the selection criteria involves the following:

- Rural and urban locations,
- Age,
- Under-served, waiting list,
- Satisfaction level, and
- Family involvement/advocacy.

Additionally there are possible system-related questions:

- Do self-directed services promote expanding the provider network;
- Is there a change in satisfaction level as a result of self-directed supports;
- Do self-directed services alter the budget levels; and
- What quality measures work or need altering.

The second set of decisions is to decide what services are to be included. In the pilot it is recommended that a limited scope of services be included, such as a) respite, b) supported employment, c) personal support/personal care/attendant care, and d) transportation. Other services raise significant policy-related, budget, and system change implications and the recommendation is to implement these changes later.

The third set of decisions is related to rates. Portability of rates is a critical component for self-directed services. Rates do not need to be uniform but the variance in rates for similar services also cannot be great. A fee schedule with a range may need to be developed, at least for the initial implementation. Additionally, how will under-spending the allocation be addressed? Conversely, how will overspending be prohibited?

A fourth set of decisions is what are the quality measures, including health and safety. Self-directed supports are different from existing services and they probably should be measured and evaluated differently. There does not exist a need to have fully developed monitoring systems

prior to pilot. There should be certain decisions around what are the outside parameters for the public funds and the essential or minimal qualifications for individuals hired by consumers.

The fifth set of decisions is related. The essential issue centers on who is eligible to become a provider and what prerequisite will be in place as a condition of payment.

The last set of decisions centers on whether Medicaid funds will be available and under what conditions will payments be made or denied.

Step 2: Define the questions to be addressed during the pilot

The pilot should focus first on individuals with developmental disabilities and test system components that maximize successful consumer-directed services. The following components should be examined:

- Develop, implement, and evaluate the process that allocates and monitors resources awarded to an individual with developmental disabilities. The objective of the pilot will be to answer the following questions:
  1. How will the objectives and needs identified in the plan be translated into resource allocations?
  2. What will be the measure of "reasonableness"?
  3. How will resources actually be allocated, in particular Medicaid dollars?
  4. What occurs if resources are over-expended or under-expended?
  5. What is the service authorization process?
  6. Who pays the service provider and how timely is the process?
  7. What is the employer/employee relationship?

- Develop the prior-authorization levels and determine what "triggers" would require a review;
- Identify system barriers and develop strategies to remove obstacles with a particular focus on regulations, rules, and policies that should be modified;
- Develop and implement ongoing information and educational sessions for people with developmental disabilities, families, staff, and other policy-makers on consumer-directed services and supports. Identify changes in system design and the rationale for such changes;
- Identify the outcomes both at the individual and system level to be used to measure the effectiveness of consumer-directed services.

Provider Impact:

Consumer-directed services are not a new type of support. Rather, the essence of consumer-directed services is a fundamental change in how supports are structured and made available to people who require the assistance. Consequently, consumer-directed supports will have a significant impact on service providers (including state systems).

The proposed pilot should be designed to measure and assist service providers in reconfiguring their organizations to meet the demands and expectations associated with consumer-directed supports.

Step 1: Conduct business planning

Moving away from capacity funding to an on-demand system requires planning and retooling of an organization's administrative structure, especially if the organization is heavily invested in property (group homes, congregate program settings). The evidence to date is that people with developmental disabilities, when given the options, tend to select different methods of supports than the traditional array of services. Concomitantly, the availability of trained and competent support staff is critical and the ability to offer regular and relief/backup workers is critical for the system to be viable. Consumer-directed supports are highly dependent on the evolution of existing network of service providers (including state services). Business planning is the recommended strategy to begin or escalate the evolution.

Step 2: Selection of providers

A minimum of two service provider organizations should be selected, one representing non-profits and the other for-profit corporations. The providers must currently offer the services to be included in the pilot and also provide congregate services either as group home providers or as providers for congregate program supports. The provider agencies should be geographically and programmatically linked to the people with developmental disabilities selected to participate in development of individual budgets in order to gauge the impact on the providers' organization.

Step 3: Define the issues to be evaluated during the pilot

In addition to the impact of moving away from capacity to on-demand supports, there are other inquiries that should be included in the pilot. These can include:

- The cost of providing services within community settings,
- Impact on staff turnover,
- Changes required in policies and staff training,
- IS0 functions and relationships,
- Types of system planning required to ensure an array of providers for consumer-directed supports, and
- What quality indicators and measures for outcome are applicable and doable.

Attachments

Provider Survey Tool

- Provider Readiness Tool
- On site Interview Tool

Center for Outcome Analysis Survey Instrument and National Baseline Data

List of Interviewees – DMR, MAA, and Providers

List of Mercer Staffing and Consultants

Financial Data Sources

National Salary/Compensation Data

Provider Readiness Review Summary Comments

Center for Outcome Analysis National Baseline Data

Center for Outcome Analysis Sampling Methodology

SELF-DETERMINATION (SD) READINESS REVIEW
PROVIDER SITE QUESTIONNAIRE

Name of Provider Agency:			
Agency Address (Main Office):			
Agency Phone/Fax #:			
Agency Type (Please Circle):	**Not-for Profit**	**For-profit**	**Other (Please indicate)**
Name(s)/Title(s) of Person(s) Completing Questionnaire:			
E-Mail Address for above Person(s) (if applicable):			

Background Questions	Provider Response	Review/Comments
• **What** types of contracted services (e.g. in-home support services) does your agency provide for people with disabilities (we will use the term "consumer' throughout this questionnaire) and their families?		
• How many consumers receive each of your specific contracted services? Please list by service type. If you are a multiple service provider (e.g. employment and residential supports) this may be a **duplicated** count.		
• What is the total number of consumers you support in your contracted services? Please use an **unduplicated**		

• Do you believe that your new employee orientation, employee training and job descriptions are consistent with SD or related principles?		
• Are consumer/families involved in any part of the employee hiring/evaluating/firing process? If so, how?		
Financial Questions	**Provider Response**	**Review/Comments**
• (If any sites are owned by the provider or related parties) Do you see this ownership as a barrier to service choice by the consumer or family?		
• Is your current pay and benefits package sufficient to attract qualified direct care workers? If not, what would it have to be competitive?		

• What is the lowest level in your organization at which employees are knowledgeable of service reimbursement rates? Internal budgets for a given service?		
Management Questions	**Provider Response**	**Review/Comments**
• Given your familiarity with SD principles, how do you believe your vision/mission/philosophy "fits" with SD?		
• Do you believe you have an adequate management/business infrastructure to support SD implementation? What are your strengths and needs in this area?		
• Are your BOD and/or advisory board members aware of SD principles? If aware, are they supportive?		

• Do you believe your current assessment of consumer satisfaction measures personal outcomes? If not, how do you believe it could be changed to reflect a personal outcome orientation?		
Planning/Budgeting Questions	**Provider Response**	**Review/Comments**
• Does the consumer have any influence or control of who attends required consumer planning meetings? Does the consumer or family member ever facilitate these meetings?		
• Does the consumer or family have any influence or control of the financial resources available to the consumer? If so, to what extent?		

• Is there presently a fiscal intermediary or service brokerage service available to consumers supported by your agency?		
Marketing Questions	**Provider Response**	**Review/Comments**
• Does your provider brochure or other marketing materials reflect SD-related principles? If not, are you presently considering any changes?		
Community Questions	**Provider Response**	**Review/Comments**
• Do any of the community organizations (i.e. local, sate, national, etc.) to which you belong (i.e. advocacy, self-advocacy, provider, etc.) encourage SD?		

• Assuming some implementation of SD principles here, do you see your agency working any differently with other community organizations?		
Overall Questions	Provider Responses	Review/Comments
• In general or specifically, if your organization were to practically embrace SD principles, what would it have to do differently, if anything, to successfully support consumers and families?		
• In general or specifically, if the State of Kentucky were to practically embrace SD principles, what would it have to do differently, if anything, to successfully support providers, consumers and families?		

SELF-DETERMINATION (SD) READINESS REVIEW
ON-SITE QUESTIONNAIRE (JUNE 2001)

Name of Provider Agency:
Agency Address (Main Office):
Agency Phone/Fax #:
Name(s)/Title(s) of Person(s) Interviewed:
E-Mail Address for above Person(s) (if applicable):

Background Questions	Provider Response	Review/Comments
• What does the term "self-determination" mean to you as a provider? (SHARE A COPY OF **"WHAT IS SELF-DETERMINATION?"** WITH THE PROVIDER NOW).		
• Does the term "self-determination" have any meaning for your typical direct care worker? If so, what meaning?		
• Are you familiar with the term "people First language?" (If not, explain). Does your organization presently support the use of this language?		

count for this total.		
• How many physical sites do you have for each of your contracted services? What is the total number of sites?		
• How many total employees do you have? Of this total, how many are part-time (less than 30 hrs/week)?		
• What is your turnover rate, if any, for your direct service workers during the past year (e.g. 50%)?		
• Do you have written job descriptions for your direct support workers? If so, please attach one example from one of your contract&G&ices. If not, are you planning to develop them?		

Financial Questions	Provider Response	Review/Comments
• What is the **estimated** annual budget for each of your contracted services. What is your **estimated** total annual budget for all committed services?		
• What are the sources of your funding (by percent) for your total annual budget (e.g. 45% ICF, 45% waiver and 10% donations)?		
• How many, if any, of your contracted service sites are owned by your agency, a related entity (e.g. holding company), a Board of Directors member, you or a family member? If applicable, please specify by site and contracted service.		

• What is the typical entry-level pay/range for direct support workers for each of your contracted services?		
• What are the typical entry-level benefits for direct support workers? When do those benefits "kick in" (e.g. health insurance after the first 90 days of employment)?		
Management Questions	**Provider Response**	**Review/Comments**
• Do you have a statement of vision, mission, values and/or philosophy? If so, please attach. If not, you may attach a brief statement for this questionnaire.		
• Do you have a written business plan? If so, please indicate the primary goals of your plan (you can attach the		

relevant sections of your plan if you wish). If not, do you intend to develop one?		
• Do you have an organizational chart? If so, please attach. If not, please draft one and attach for this review.		
• Do you have a Board of Directors (BOD)? If so, what is the composition of your BOD (e.g. 2 family members, 5 community leaders, 1 consumer)? If so, how often does the BOD meet?		
• Do you have a consumer/family advisory board? If so, what is it's role? If so, how often does it meet? If not, are you nterested in developing one?		

• Do you utilize any measure of consumer/family satisfaction or personal outcomes? If so, please attach a copy of your most recent survey form. If not, are you interested in developing one?		
• What types of outcome or quality assurance data, if any, do you collect? If applicable, do you report it to your funding source? If applicable, **briefly** identify per funding source.		
Planning/Budgeting Questions	**Provider Response**	**Review/Comments**
• What type of printed format, if any, do you use for required (e.g. annual ISP) consumer planning meetings? If applicable, please attach a copy.		
• Who typically facilitates these required consumer planning meetings?		

• Are consumer budgets, consumer financial resources, provider reimbursement rates or other financial information discussed at these required planning meetings? If so, is there a printed format for organizing and reviewing this financial information? If applicable, please attach a copy.		
Marketing Questions	**Provider Response**	**Review/Comments**
• How do you market your services?		
• Do you have a brochure or service description that you give to potential consumers/families? If so, please attach.		

if not, do you plan to develop one?		
• Do you use or rely on any other forms of marketing (e.g. work-of-mouth), fundraising events, newspaper articles, etc.)? If **so, briefly** describe.		
Community Questions	**Provider Response**	**Review/Comments**
• Does your agency sponsor/co-sponsor any community activities for consumers/families. If so, please list		
• Is your agency involved with any self-advocacy organizations? If so, please identify.		

• Is your agency involved with any self-advocacy (led by consumers) organization? If so, please identify.		
• Is your agency involved with any local, statewide or national provider organizations? If so, please identify.		
Questions/Comments	**Provider Response**	**Review/Comments**
• Please list any questions or comments, and attach additional pages as necessary.		

YEAR 2001 SURVEY OF PEOPLE IN SUPPORTED COMMUNITY LIVING AND THEIR FAMILIES

)ear Sir or Madam:

'he Center for Outcome Analysis is doing a statewide survey of people who are involved in Supported lommunity Living in Kentucky. We've been asked to do this on behalf of the Kentucky Department of Medicaid Services, Division of Long Term Care.

'he Department is interested in finding out about your life, what you think about your living situation, what you rink about your daily activities, and whether you might be interested in finding out more about Self-)etermination. Self-Determination is a way to get more choices made by you and your families and friends, in ooperation with the staff and case managers who work with you. Self-Determination includes making choices bout how to use the money that supports you. Self-Determination is done gradually and responsibly, so that no ne will have to make more choices than they are comfortable with.

'his survey is for you. If you need help in answering the questions, that's fine.

)n most questions, just circle the number next to the answer that's most true for you.

'here's another envelope in with this survey, and that one is for your closest relative. We want to find out what hey think, too. If possible, please put their address on the envelope and mail it to them --- or, just give it to hem when you see them. The questions we want to ask them are just about the same as the ones we're asking 'ou.

1. Complete the attached form and mail it back in the enclosed stamped envelope,

)R:

2. Write your name and telephone number in the space provided below and mail this letter back to us in the enclosed envelope. We will contact you to arrange a phone interview.

Name_____ Phone #_____

We hope you will fill out this survey. Please let your voice be heard.

Sincerely,

James W. Conroy, Ph.D., President
The Center for Outcome Analysis
20 1 Sabine Avenue
Narberth, PA 19072
51 o-668-9001, FAX 9002, email outcomeanalysis@aol.com

Year 2001 Survey of People in Supported Community Living in Kentucky

We sent this survey to you at the address below

LABEL
PERSON'S NAME
PERSON'S ADDRESS

If this address is out of date or wrong, please write your new address here:

_____

_____

_____

1) How old are you?

_____ **years**

2) What kind of place do you live in now?

1. With relatives
2. Group home
3. Foster home
4. Supported Community Living situation
5. Independent living
6. Institutional setting (more than 15 people)
7. Other, ***please describe:*** _____

3) How many people live in your home besides you?

_____

4) Have you heard of Self-Determination for people with developmental disabilities?

No, never heard of it	Heard of it but don't know what it is	Heard of it and know a little about it	***Yes,*** and I know a fair amount about it	Yes, and I know a lot about it
1	2	3	4	5

) If you have heard of Self-Determination, have you been involved in it in any way?

No, not at all	Yes, but very little	Yes, somewhat	Yes, significantly	Yes, very much
1	2	3	4	5

) Qualities of Life

ease give your opinion of your qualities of life "A YEAR AGO" and "NOW." We are trying to find out if you ink your life is better, worse, or about the same as it was a year ago.

A YEAR AGO 1 - Very Bad 2 – Bad 3 – OK 4 – Good 5 - Very Good	**Life Area**	*NOW* 1 Very Bad 2 Bad 3 0 K 4 Good 5 Very Good
1 2 3 4 5	1) Health	1 2 3 4 5
1 2 3 4 5	2) Running own life, making choices	1 2 3 4 5
1 2 3 4 5	3) Family relationships	1 2 3 4 5
1 2 3 4 5	4) Seeing friends, socializing	1 2 3 4 5
1 2 3 4 5	5) Getting out and getting around	1 2 3 4 5
1 2 3 4 5	6) What he/she does all day	12345
1 2 3 4 5	7) Food	1 2 3 4 5
1 2 3 4 5	8) Happiness	1 2 3 4 5
1 2 3 4 5	9) comfort	12345
1 2 3 4 5	10) Safety	1 2 3 4 5
1 2 3 4 5	11) Treatment by staff/attendants	1 2 3 4 5
1 2 3 4 5	12) Health care including dental	1 2 3 4 5
1 2 3 4 5	13) Privacy	1 2 3 4 5
1 2 3 4 5	14) Overall quality of life	1 2 3 4 5

) WHAT'S MOST IMPORTANT TO YOU?

FIVE MOST IMPORTANT THINGS © J.W. Conroy 2001

or you, what are the **five most important things** about having a good life?

ease read through the list below and determine which of these is the #1 most important thing to you about your well-being? Please write a " 1" next to that item. Then, please write a "2" next to the SECOND most important thing to you. Please continue writing numbers up to 5, for the fifth most important thing to you. Don't write any numbers above 5, please.

Imnortant to You	
_____	Assistive devices
_____	Being kept busy
_____	Being with other people with disabilities
_____	Choicemaking
_____	comfort
_____	Communication
_____	Community acceptance
_____	Supports for problematic behavior
_____	Development, learning
_____	Dignity, respect
_____	Earn money
_____	Exercise, fitness
_____	Family-like atmosphere
_____	Freedom from abuse
_____	Friends
_____	Girlfriends/Boyfriends
_____	Health
_____	Home-like place
_____	Integration, inclusion
_____	Large facility to live in
_____	Love
_____	Medical attention
_____	Monitoring the quality of services
_____	Permanence of home
_____	Productive day activities
_____	Religion, worship
_____	Safety
	Self esteem
_____	Self-care skill development
_____	Self-determination
_____	Stability
_____	Travel, vacations
_____	Working for pay

(8) Who Chooses?

sk the respondent to say who actually makes decisions in each area as shown, from 0 to 10. a r e ade entirely by PAID PERSONNEL (program staff, Case Manager, agency officials, doctors, etc.), enter "0" r that area. If decisions are made entirely by the PERSON AND/OR TRUSTED FRIENDS, RELATIVES, DVOCATES, etc., enter "10." If decisions are equally shared, enter "5." UNPAID can include people who d a relationship with the person before they began receiving money for their support, such as a sibling or :ighbor. Items can be left blank, Next, rate each area for "How Important" it is for the person and the person's rcle to have control in each area.

'HO MAKES DECISIONS?
0---1---2---3---4---5---6---7---8---9---10
uid **Person and/or Trusted**
.aff **Unpaid Friends, Relatives, Advocates**

WHO		
		FOOD
	1P	What foods to buy for the home when shopping
		CLOTHES AND GROOMING
	5P	What clothes to buy in store
	8P	Time and frequency of bathing or showering
		SLEEP AND WAKING
	10P	When to go to bed on weekends
	12IP	Taking naps in evenings and on weekends
		RECREATION
	13P	Choice of places to go
____	14P	What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.
	15P	Visiting with friends outside the person's residence
		SUPPORT AGENCIES AND STAFF
____	20P	Choice of Case Manager
	22P	Choice of support personnel: option to hire and tire support personnel
		ECONOMIC RESOURCES
	24P	How to spend residential funds
	25P	How to spend day activity funds
		HOME
	27P	Choice of people to live with
		WORK OR OTHER DAY ACTIVITIES
	29P	Type of work or day program
		OTHER
	34P	Whether to have pet(s) in the home
	35P	When, where, and how to worship

9) Planning Team

Vho usually comes to your Individual Planning meetings (also called IPP meetings, IHP meetings, ELP neetings, Person-Centered Planning meetings, and lots of other names)?

____ how many who are paid to come?

____ how many who are not paid to come?

____ how many altogether?

10) How much do you know about the money that's being spent to support you?

Nothing	A Little	Some	A Lot	Everything
1	2	3	4	5

1) How much altogether is being spent to support you each year?

(enter 9 if don't know)

COMMENTS

2) Please write any comments you have about Supported Community Living in Kentucky. (Or about **elf-Determination,** if you want to.)

3) If you had one wish to be granted, what would it be?

4) Did you have help answering these questions?

No, not at all	Yes, but very little	Yes, somewhat	Yes, significantly	Yes, very much
1	2	3	4	5

5) If yes, who helped?

Staff	Family	Friend	Other
1	2	3	4

THANK YOU!

his section is almost the exact same survey we did with the original self-etermination participants' families in New Hampshire in 1996. Nonetheless, now must be revised to conform with the person-centered survey above. We've arned a lot since then. This revision should take about 6 hours. Ideally, we would o a pilot test with 9 families to look for flaws.

Year 2001 Survey of the Families of People in Supported Community Living in Kentucky

This survey is about:

LABEL
PERSON'S NAME
AND IDENTIFICATION CODE

We sent this survey to you at the address below

LABEL
FAMILY NAME
FAMILY ADDRESS

If this address is incorrect, please write your new address in the space provided below.

) What is your relationship to the person named above? (PLEASE CIRCLE A UMBER)

1. Mother
2. Father
3. Mother and Father (responding together)
4. Sister or Brother
5. Grandmother or Grandfather
6. Aunt or Uncle
7. Not Related --- Guardian or Conservator
8. Not Related --- Friend of Person or Person's Family
9. Other (PLEASE SPECIFY): _____

) How old is your relative?

_____ years or __ Don't Wish To Answer

) OPTIONAL: How old are you?

_____ years or __ Don't Wish To Answer

) What kind of place does your relative live in now?

1. With us or with other relatives
2. Group home
3. Foster home
4. Supported living situation
5. Independent living
6. Institutional setting (more than 15 people)
7. Other, *please describe:* _____

) How many people live in your relative's home (including your relative)?

_____

13) Have you heard of Self-Determination for people with developmental disabilities?

No, never heard of it	Heard of it but don't know what it is	Heard of it and know a little about it	Yes, and I know a fair amount about it	Yes, and I know a lot about it
1	2	3	4	5

4) If you have heard of Self-Determination, has your relative been involved in it in any ay?

No, not at all	Yes, but very little	Yes, somewhat	Yes, significantly	Yes, very much
1	2	3	4	5

i) Qualities of Life

Please circle numbers to describe your opinions about the qualities of your relative's life **THREE YEARS AGO** and his/her qualities of life **NOW.** For any that you don't know, just don't circle anything.

Quality of Life Changes

lease give your opinion of your relative's qualities of life "A YEAR AGO" and "NOW." We :e trying to find out if your relative's life has gotten better, worse, or stayed the same.

A

A YEAR AGO 1 - Very Bad 2 – Bad 3 – OK 4 – Good 5 - Very Good	**Life Area**	***NOW*** 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good
1 2 3 4 5	15) Health	1 2 3 4 5
1 2 3 4 5	16) Running own life, making choices	1 2 3 4 5
1 2 3 4 5	17) Family relationships	1 2 3 4 5
1 2 3 4 5	18) Seeing friends, socializing	1 2 3 4 5
1 2 3 4 5	19) Getting out and getting around	1 2 3 4 5
1 2 3 4 5	20) What he/she does all day	1 2 3 4 5
1 2 3 4 5	21) Food	1 2 3 4 5
1 2 3 4 5	22) Happiness	1 2 3 4 5
1 2 3 4 5	23) Comfort	1 2 3 4 5
1 2 3 4 5	24) Safety	1 2 3 4 5
1 2 3 4 5	25) Treatment by staff/attendants	1 2 3 4 5
1 2 3 4 5	26) Health care including dental	12 3 4 5
1 2 3 4 5	27) Privacy	1 2 3 4 5
1 2 3 4 5	28) Overall quality of life	1 2 3 4 5

2) What is your relative's status with guardianship or conservatorship?

1. Parent or other relative is full guardian
2. Parent or other relative is limited guardian (including conservatorship)
3. Unrelated person is full guardian
4. Unrelated person is limited guardian (including conservatorship)
5. Person has no guardian or is own guardian, not adjudicated incompetent

11) How many times, if any, has your relative changed homes in the past year?

____ times in the past year

.2) About how often were you able to visit your relative in the past year?

____ times in the past year

3. **Involvement:** About how often do you have the following kinds of contact with your :lative? **(Ship this question if your relative lives with you.)**

.bout how
ften in the
ast year?
Zero if none)

_____ 10a. Telephone calls (including talking with staff)

_____ 10b. Mail

_____ 10c. Visits at your relative's home

_____ 10d. Taking your relative out

_____ 1 Oe. Program Planning Meetings

_____ 10f. Consent for medical care

17) Do you know your relative's service coordinator?

1. Yes
2. No

18) How satisfied are you with your relative's service coordinator?

Very Dissatisfied	Dissatisfied	In Between, Neutral	Satisfied	Very Satisfied
1	2	3	4	5

19) How involved are you in meetings and planning sessions about your relative?

Not at All	Only a Little	A Fair Amount	Actively Involved	Very Actively Involved

1	2	3	4	5

24) FIVE MOST IMPORTANT THINGS

In the section below we would like to know what the five most important things are to you concerning your relative's well-being.

lease read through the list below and determine which of these is the #1 most important thing to you about your relative's/ward's well-being? Please write a " 1" next to that item. Then, please write a "2" next to the SECOND most important thing to you. Please continue writing numbers up to 5, for the fifth most important thing to you.

'moortant to You	
_____	Assistive devices
_____	Being kept busy
_____	Being with other people with disabilities
_____	Choicemaking
_____	comfort
_____	Communication
_____	Community acceptance
_____	Supports for problematic behavior
_____	Development, learning
_____	Dignity, respect
_____	Earn money
_____	Exercise, fitness
_____	Family-like atmosphere
_____	Freedom from abuse
_____	Friends
_____	Girlfriends/Boyfriends
_____	Health
	Home-like place
_____	Integration, inclusion
_____	Large facility to live in
_____	Love
_____	Medical attention
	Monitoring the quality of services
_____	Permanence of home
_____	Productive day activities
_____	Religion, worship
_____	Safety
_____	Self esteem
_____	Self-care skill development
_____	Self-determination
_____	Stability
_____	Travel, vacations
_____	Working for pay

COMMENTS

16) Please write any comments you have about the Self-Determination Initiative.

27) If you had one wish for your relative, what would it be?

THANK YOU!

Self-Determination Feasibility Study: Provider Interviews Conducted

- Cedar Lake
  Louisville, Kentucky
- Community Alternatives Kentucky- Bluegrass
  Frankfort, Kentucky
- Community Alternatives Kentucky- Green River
  Owensboro, Kentucky
- Community Alternatives Kentucky- Winchester
  Morehead, Kentucky
- CommuniCare
  Elizabethtown, Kentucky
- Community Presence
  Grayson, Kentucky
- Community Provisions
  Manchester, Kentucky
- Dreams With Wings
  Louisville, Kentucky
- Everyday Matters
  Frankfort, Kentucky
- Four Rivers
  Paducah, Kentucky
- Kaliedescope
  Louisville, Kentucky
- Kentucky River ComCare
  Hazard, Kentucky
- Laurel Springs
  London, Kentucky
- Life Skills
  Bowling Green, Kentucky

- Louisville Diversified Services
  Louisville, Kentucky
- Mountain CompCare
  Prestonsburg, Kentucky
- New Foundations
  London, Kentucky
- North Kentucky Community Care
  Covington, Kentucky
- Pathways
  Ashland, Kentucky
- Penny Royal
  Hopkinsville, Kentucky
- ResCare
  Statewide
- Seven Counties Services
  Louisville, Kentucky
- Strategic Partnerships
  Owensboro, Kentucky
- Supported Living of Northern Kentucky
  Covington, Kentucky
- WATCH
  Murray, Kentucky

Self-Determination Feasibility Study: State Interviews Conducted

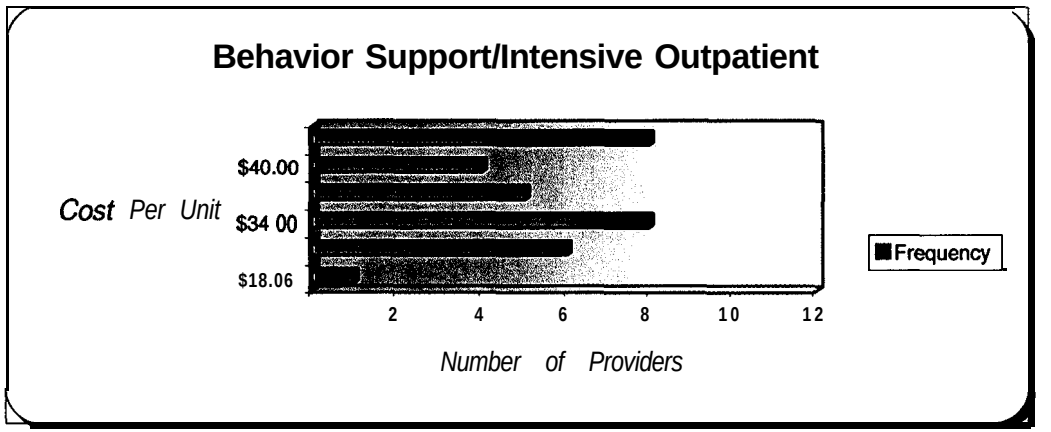
- Marilyn Duke, Director
  Commonwealth of Kentucky, Division of Long Term Care
- Kristina Reece
  Commonwealth of Kentucky, Division of Long Term Care
- Joe Arnold
  Commonwealth of Kentucky, Division of Long Term Care
- Sherry Redman
  Commonwealth of Kentucky, Division of Long Term Care
- Kevin Lightel
  Commonwealth of Kentucky, MHMR Department
- Betsey Dunnigan, RN
  Commonwealth of Kentucky, MHMR Department
- Beverly Collins
  Commonwealth of Kentucky, MHMR Department

Self-Determination Feasibility Study:
William M. Mercer
Team of Interviewers

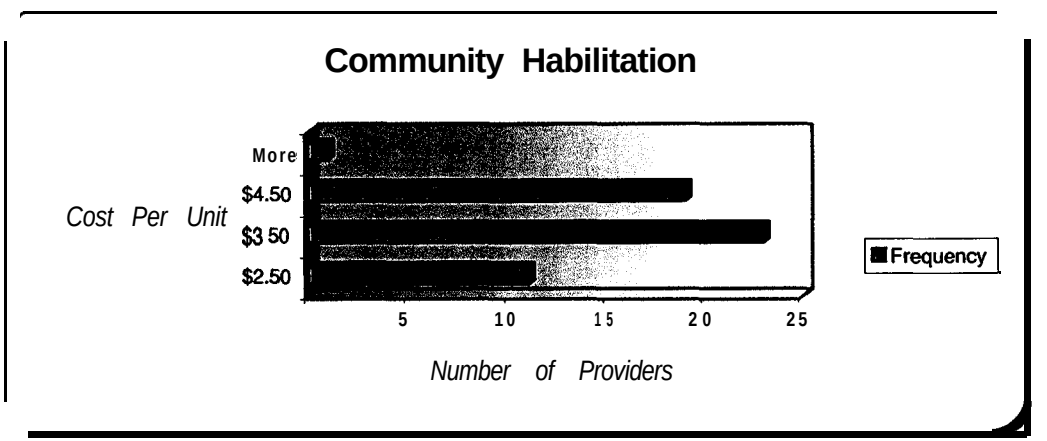
- Norm Davis
- Roger Deshaies, National Statistics Consultant
- Rob Hess, Provider Consultant
- Michelle Raliegh, Financial Consultant
- Sam Espinosa, Financial Consultant
- Kelly Williams
- Billy Ray Stokes, Provider Consultant
- Dick Smith, Provider Consultant
- Tom Schramski, Provider Consultant
- Denny Admenson, Provider Consultant
- Jim Conroy, Center for Outcome Analysis
- Ric Crowley, Consumer Consultant

Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 18.00	1	3.13%
$ 26.00	6	21.88%
$ 34.00	8	46.88%
$ 38.00	5	62.50%
$ 40.00	4	75.00%
More	8	100.00%
Mean	$ 33.11	
Min	$ 16.45	
Max	$ 42.98	
St. Dev.	$ 7.74	

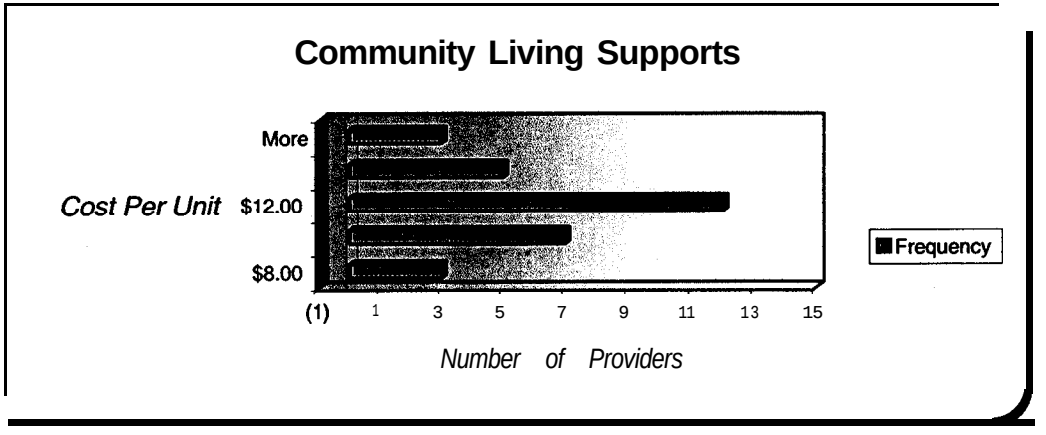


Cost Per Unit	# Providers	Cumulative %
$ 2.50	11	20.37%
$ 3.50	23	62.96%
$ 4.50	19	98.15%
More	1	100.00%
Mean	$ 3.31	
Min	$ 2.15	
Max	$ 9.42	
St. Dev.	$ 1.04	

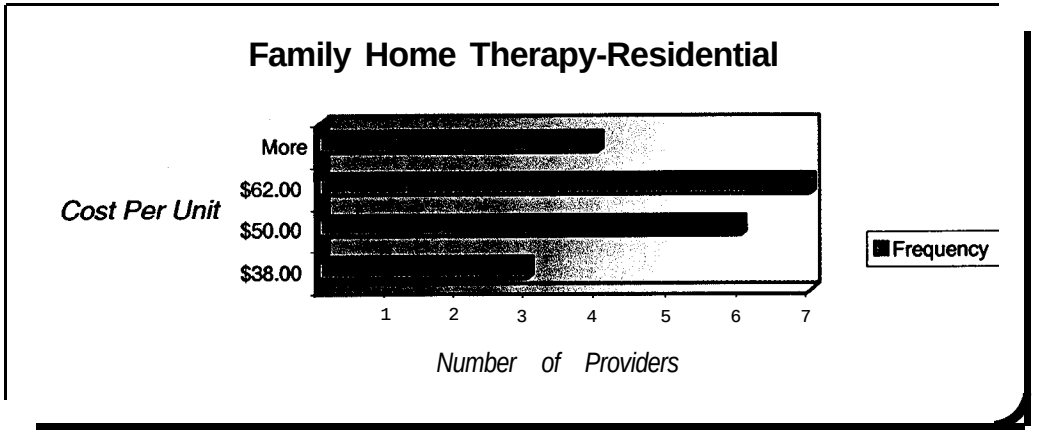


Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 8.00	3	10.00%
$ 10.00	7	33.33%
$ 12.00	12	73.33%
$ 14.00	5	90.00%
More	3	100.00%
Mean	$ 11 .00	
Min	$ 6.17	
Max	$ 17.82	
St. Dev.	$ 2.54	

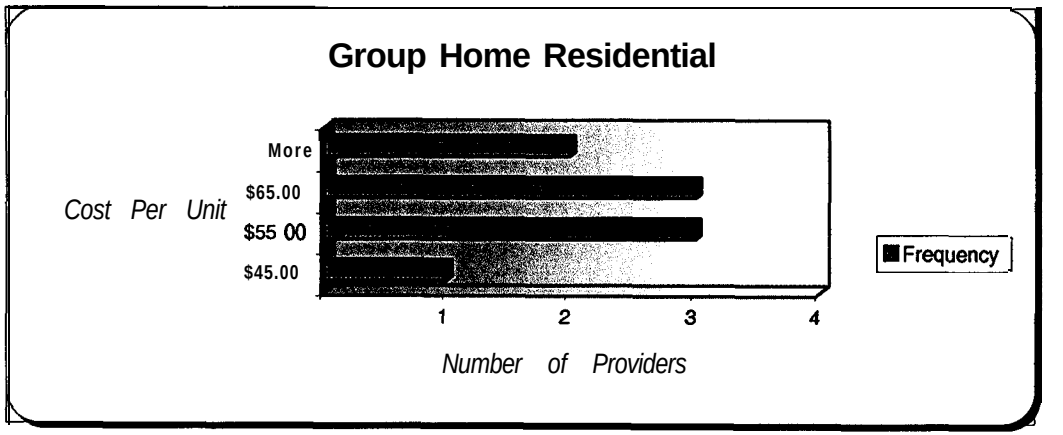


Cost Per Unit	# Providers	Cumulative %
$ 38.00	3	15.00%
$ 50.00	6	45.00%
$ 62.00	7	80.00%
More	4	100.00%
Mean	$ 50.61	
Min	$ 32.39	
Max	$ 71.77	
St. Dev.	$ 12.12	

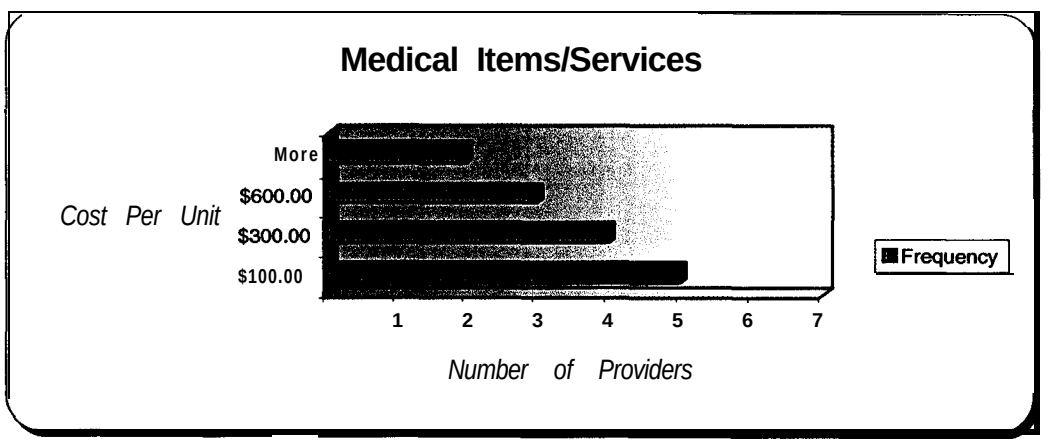


Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 45.00	1	11.11%
$ 55.00	3	44.44%
$ 65.00	3	77.78%
More	2	100.00%
Mean	$ 54.62	
Min	$ 31.03	
Max	$ 67.79	
St. Dev.	$ 11.52	

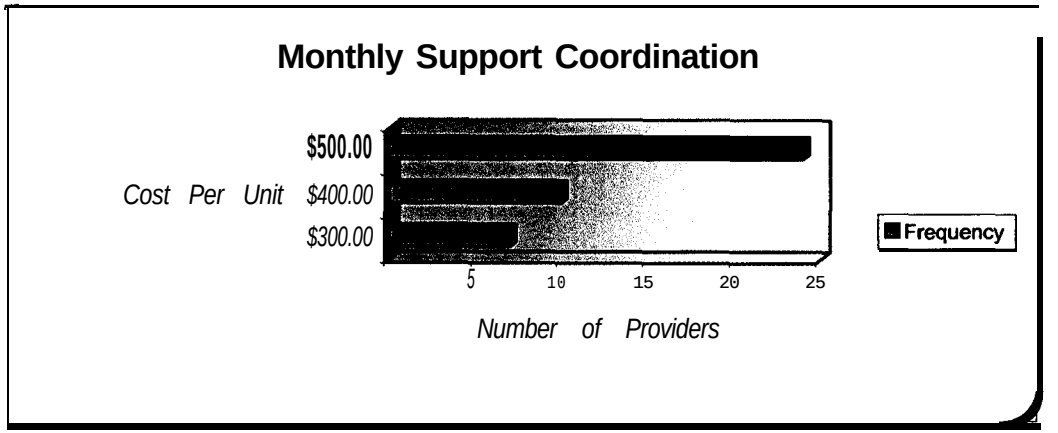


Cost Per Unit	# Providers	Cumulative %
$ 100.00	5	35.71 %
$ 300.00	4	64.29%
$ 600 .OO	3	85.71 %
More	2	100.00%
Mean	$ 247.32	
Min	$ 32.54	
Max	$ 1,556.70	
St. Dev.	$ 217.76	

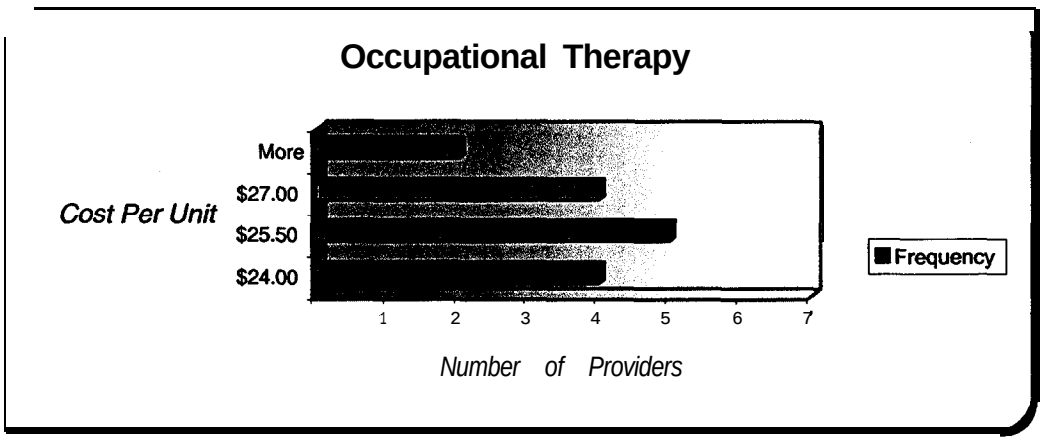


Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 300 .00	7	17.07%
$ 400.00	10	41.46%
$ 500.00	24	100.00%
Mean	$ 387.22	
Min	$ 218.72	
Max	$ 466.50	
St. Dev.	$ 69.87	

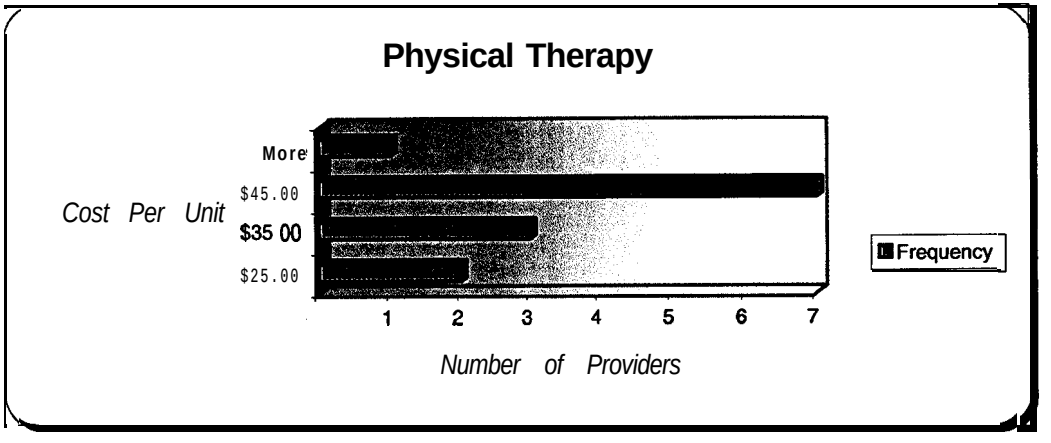


Cost Per Unit	# Providers	Cumulative %
$ 24.00	4	26.67%
$ 25.50	5	60.00%
$ 27.00	4	86.67%
More	2	100.00%
Mean	$ 24.98	
Min	$ 21.37	
Max	$ 28.96	
St. Dev.	$ 2.31	

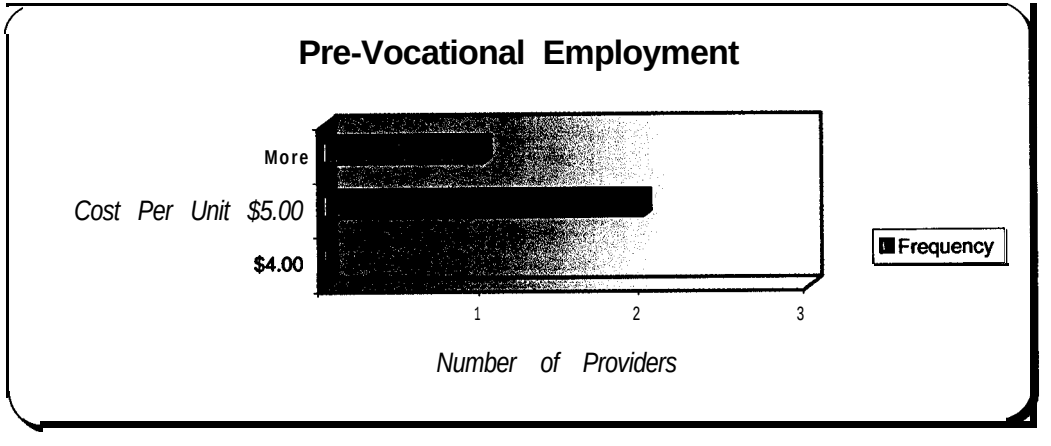


Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 25.00	2	15.38%
$ 35.00	3	38.46%
$ 45.00	7	92.31%
More	1	100.00%
Mean	$ 36.72	
Min	$ 19.48	
Max	$ 49.91	
St. Dev.	$ 9.14	

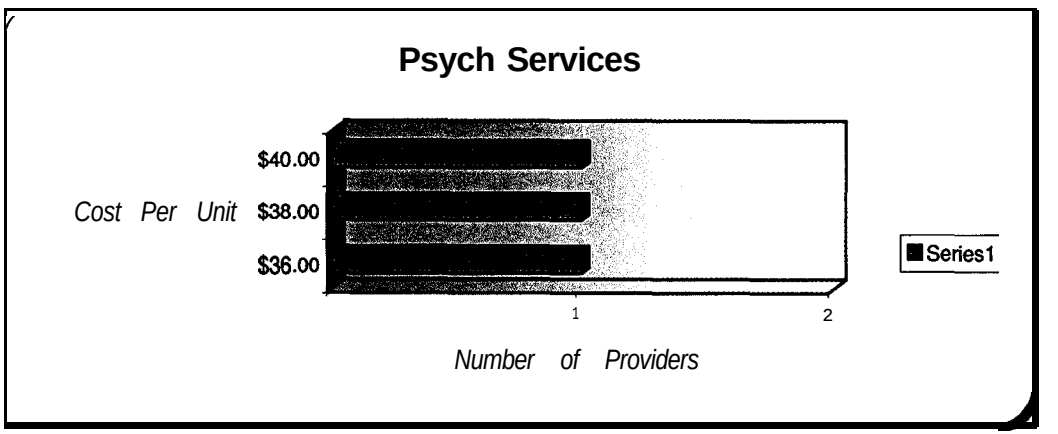


Cost Per Unit	# Providers	Cumulative %
$ 4.00	0	.00%
$ 5.00	2	66.67%
More	1	100.00%
Mean	$ 4.98	
Min	$ 4.58	
Max	$ 5.53	
St. Dev.	$ 0.49	

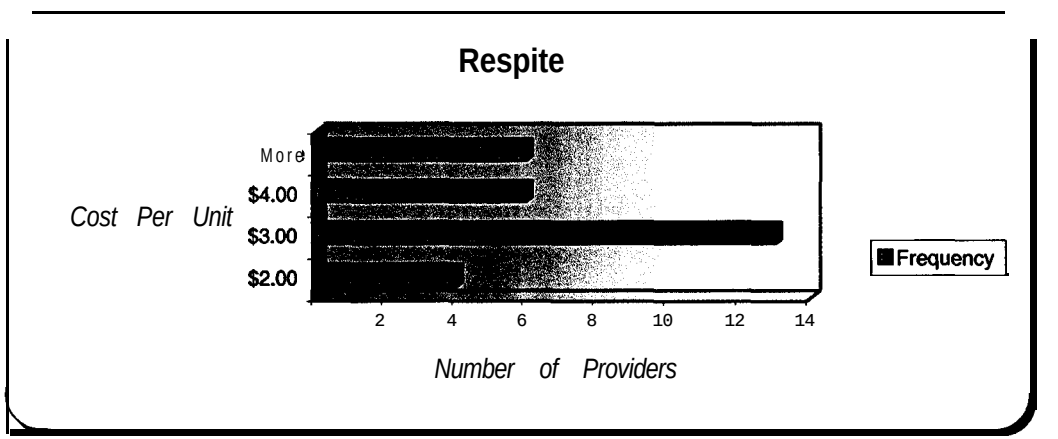


Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 36.00	1	33.33%
$ 38.00	1	66.67%
$ 40.00	1	100.00%
More	0	100.00%
Mean	$ 36.44	
Min	$ 32.06	
Max	$ 39.82	
St. Dev.	$ 3.97	

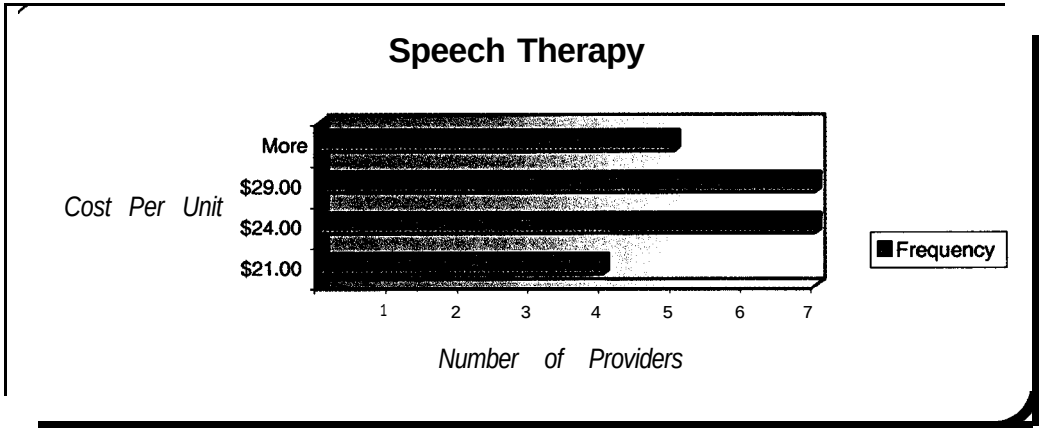


Cost Per Unit	# Providers	Cumulative %
$ 2.00	4	13.79%
$ 3.00	13	58.62%
$ 4.00	6	79.31%
More	6	100.00%
Mean	$ 3.50	
Min	$ 1.69	
Max	$ 8.74	
St. Dev.	$ 2.14	

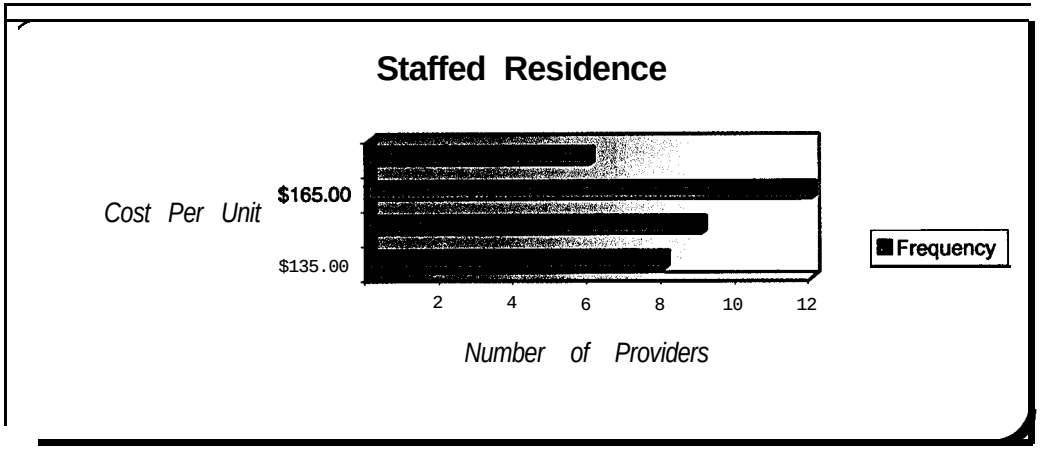


Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 21 .00	4	17.39%
$ 24.00	7	47.83%
$ 29.00	7	78.26%
More	5	100.00%
Mean	$ 25.12	
Min	$ 16.28	
Max	$ 31.20	
St. Dev.	$ 4.61	

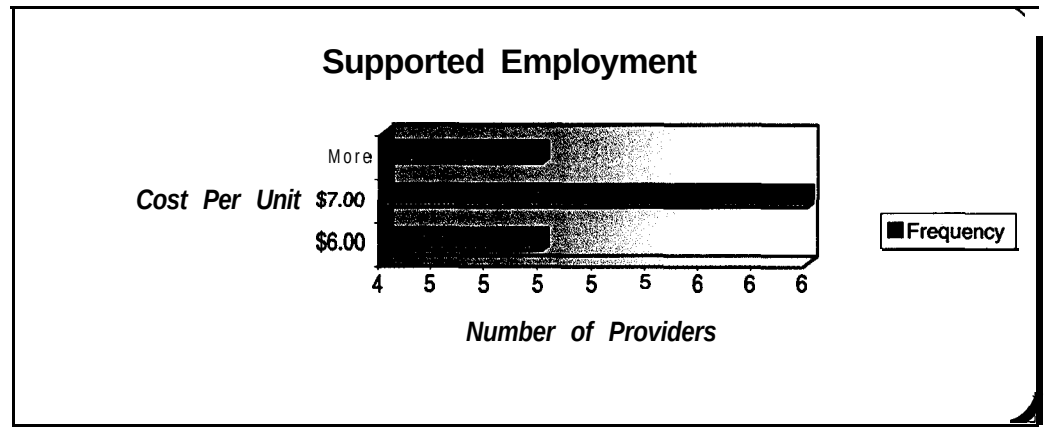


Cost Per Unit	# Providers	Cumulative %
$ 135.00	8	22.86%
$ 150.00	9	48.57%
$ 165.00	12	82.86%
More	6	100.00%
Mean	$ 146.41	
Min	$ 109.80	
Max	$ 166.67	
St. Dev.	$ 17.18	



Actual Service Cost Distribution

Cost Per Unit	# Providers	Cumulative %
$ 6.00	5	31.25%
$ 7.00	6	68.75%
More	5	100.00%
Mean	$ 7.97	
Min	$ 4.88	
Max	$ 21.48	
St. Dev.	$ 3.98	

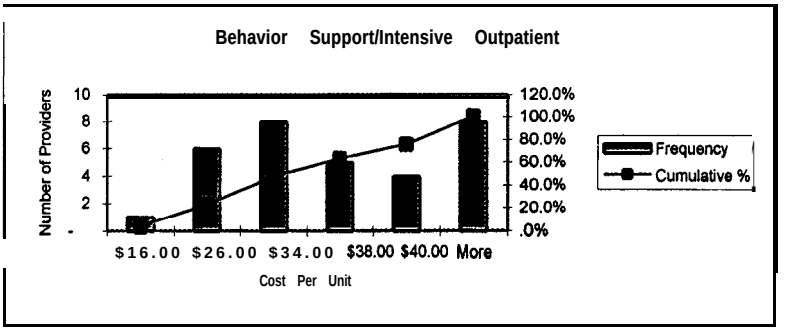


Self-Determination Feasibility Study: Financial Data Sources

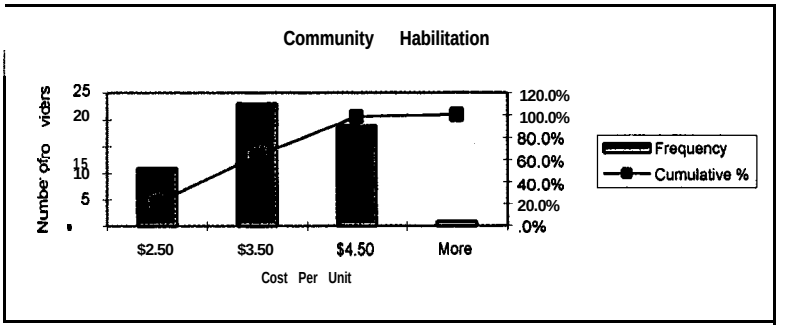
- Rate Schedule as of January 2001
- SCL Waiver Manual
- SCL Waiver Amendment (Effective 9/1/2000)
- Provider List with Claim Information provided by the Commonwealth
- Waiver Cost Summary
- Cedar Lake Financial Review On-site
- Community Alternatives Kentucky, Bluegrass Financial Review On-site

Actual Service Cost Distribution

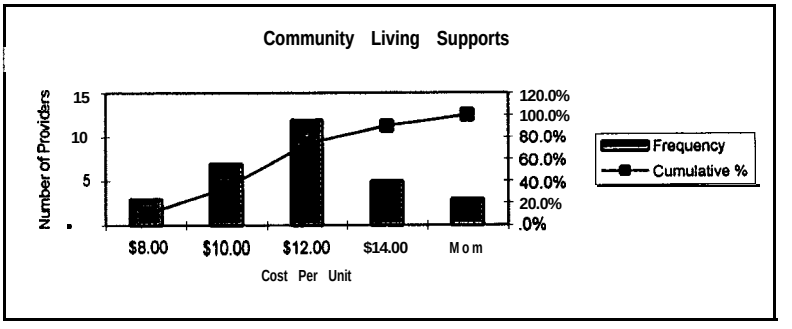
New bin	# Providers	Cumulative %
$ 18.00	1	3.13%
$ 26.00	6	21.88%
$ 34.00	8	46.88%
$ 38.00	5	62.50%
$ 40.00	4	75.00%
More	8	100.00%
Mean	$ 33.11	
Min	$ 16.45	
Max	$ 42.98	
St. Dev.	$ 7.74	



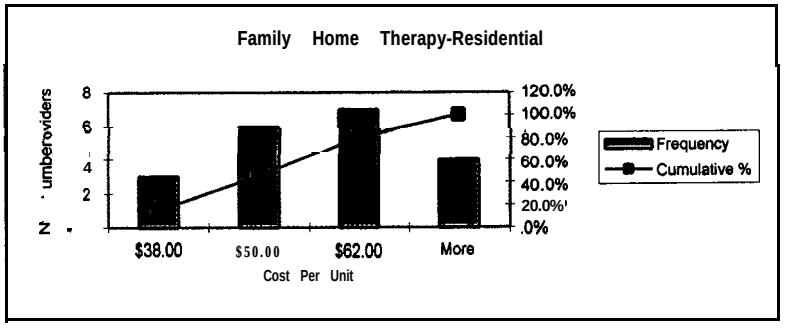
New bin	# Providers	Cumulative %
$ 2.50	11	20.37%
$ 3.50	23	62.96%
$ 4.50	19	98.15%
More	1	100.00%
Mean	$ 3.31	
Min	$ 2.15	
Max	$ 9.42	
St. Dev.	$ 1.04	



New bin	# Providers	Cumulative %
$ 8.00	3	10.00%
$ 10.00	7	33.33%
$ 12.00	12	73.33%
$ 14.00	5	90.00%
More	3	100.00%
Mean	$ 11.00	
Min	$ 6.17	
Max	$ 17.82	
St. Dev.	2.54	

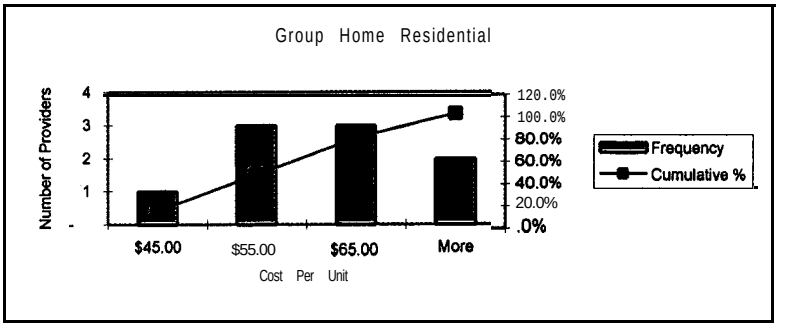


New bin	# Providers	Cumulative %
$ 38.00	3	15.00%
$ 50.00	6	45.00%
$ 62.00	7	80.00%
More	4	100.00%
Mean	$ 50.61	
Min	$ 32.39	
Max	$ 71.77	
St. Dev.	$ 12.12	

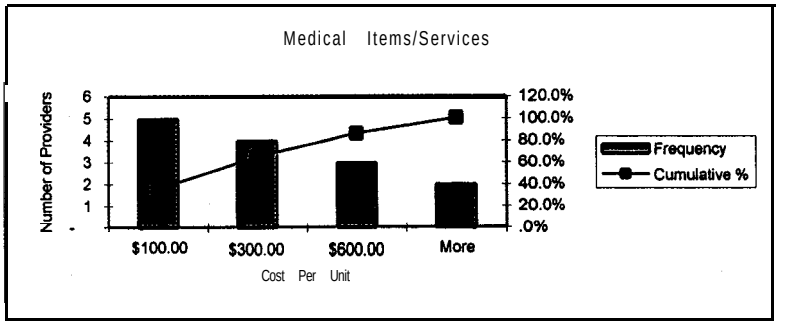


Actual Service Cost Distribution

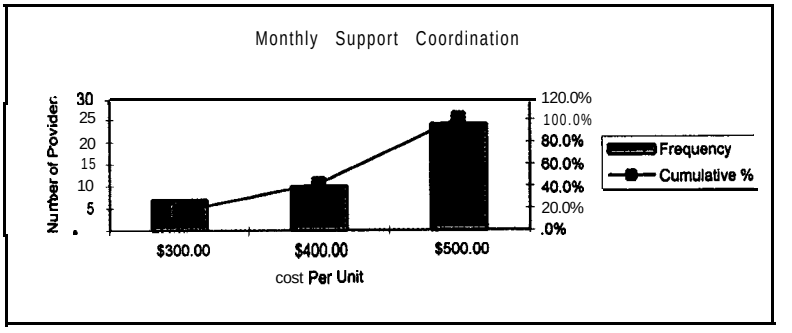
New bin	# Providers	Cumulative %
$ 45.00	1	11.11%
$ 55.00	3	44.44%
$ 65.00	3	77.78%
More	2	100.00%
Mean	$ 54.62	
Min	$ 31.03	
Max	$ 67.79	
St. Dev.	$ 11.52	



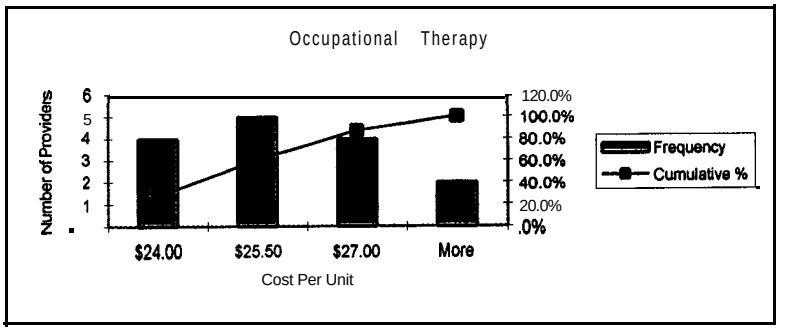
New bin	# Providers	Cumulative %
$ 100.00	5	35.71%
$ 300.00	4	64.29%
$ 600.00	3	85.71%
More	2	100.00%
Mean	$ 247.32	
Min	$ 32.54	
Max	$ 1,556.70	
St. Dev.	$ 217.76	



New bin	# Providers	Cumulative %
$ 300.00	7	17.07%
$ 400.00	10	41.46%
$ 500.00	24	100.00%
Mean	$ 387.22	
Min	$ 218.72	
Max	$ 466.50	
St. Dev.	$ 69.87	

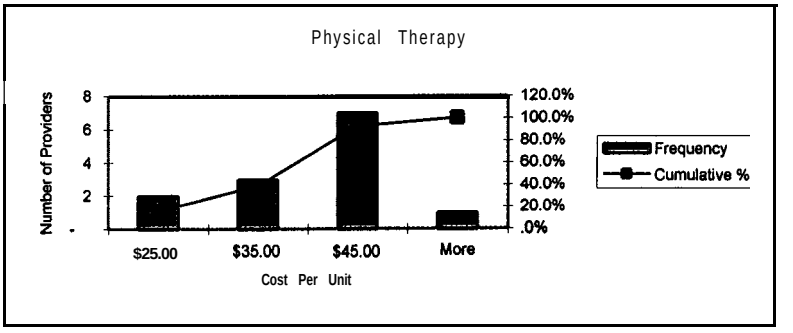


New bin	# Providers	Cumulative %
$ 24.00	4	26.67%
$ 25.50	5	60.00%
$ 27.00	4	86.67%
More	2	100.00%
Mean	$ 24.98	
Min	$ 21.37	
Max	$ 28.96	
St. Dev.	$ 2.31	

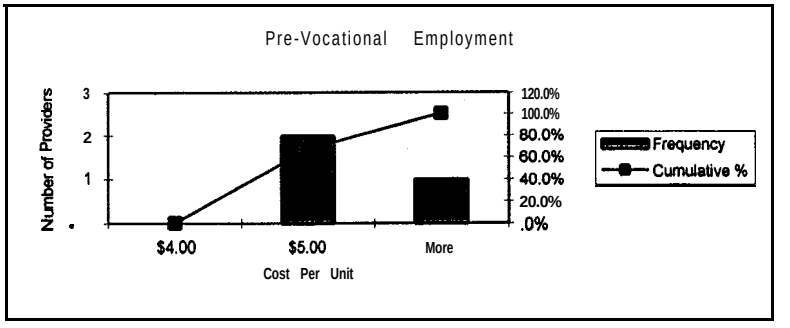


Actual Service Cost Distribution

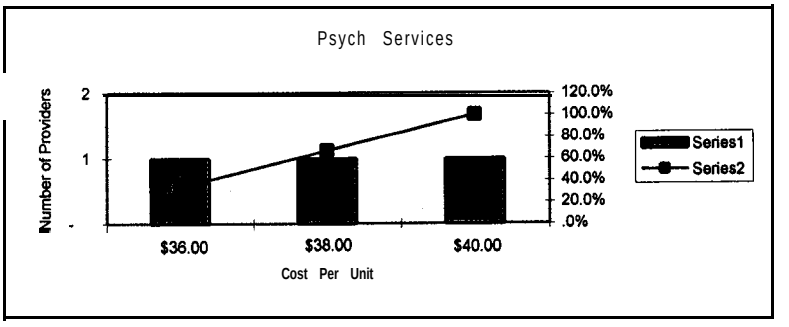
New bin	# Providers	Cumulative %
$ 25.00	2	15.38%
$ 35.00	3	38.46%
$ 45.00	7	92.31%
More	1	100.00%
Mean	$ 36.72	
Min	$ 19.48	
Max	$ 49.91	
St. Dev.	$ 9.14	



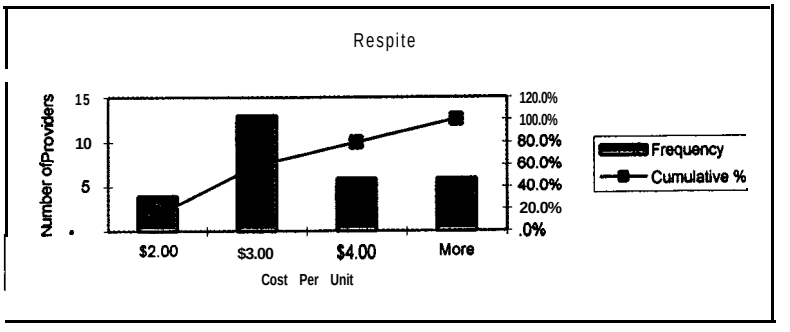
New bin	# Providers	Cumulative %
$ 4.00	0	.00%
$ 5.00	2	66.67%
More	1	100.00%
Mean	$ 4.98	
Min	$ 4.58	
Max	$ 5.53	
St. Dev.	$ 0.49	



New bin	# Providers	Cumulative %
$ 36.00	1	33.33%
$ 38.00	1	66.67%
$ 40.00	1	100.00%
More	$ 0	100.00%
Mean	$ 36.44	
Min	32.06	
Max	$ 39.82	
St. Dev.	$ 3.97	

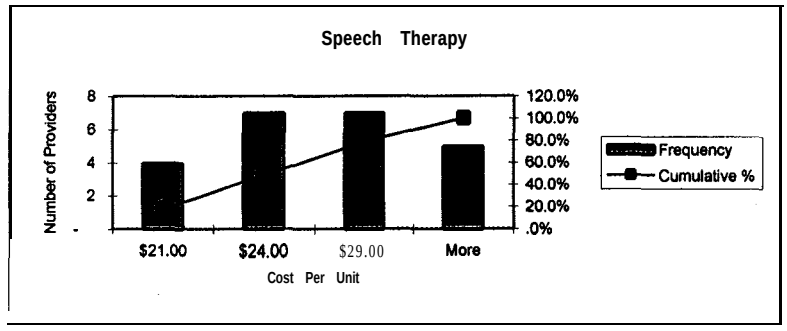


New bin	# Providers	Cumulative %
$ 2.00	4	13.79%
$ 3.00	13	58.62%
$ 4.00	6	79.31%
More	6	100.00%
Mean	$ 3.50	
Min	$ 1.69	
Max	$ 8.74	
St. Dev.	$ 2.14	

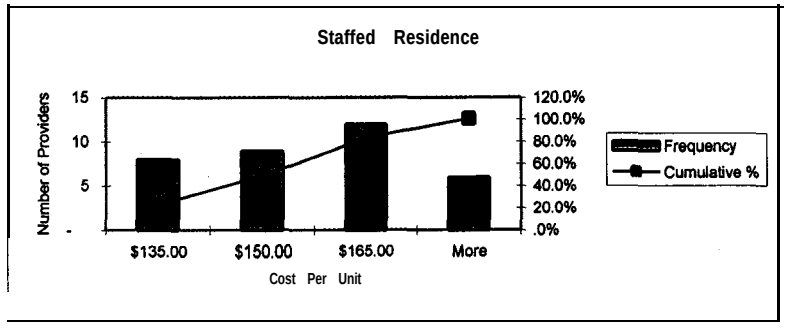


Actual Service Cost Distribution

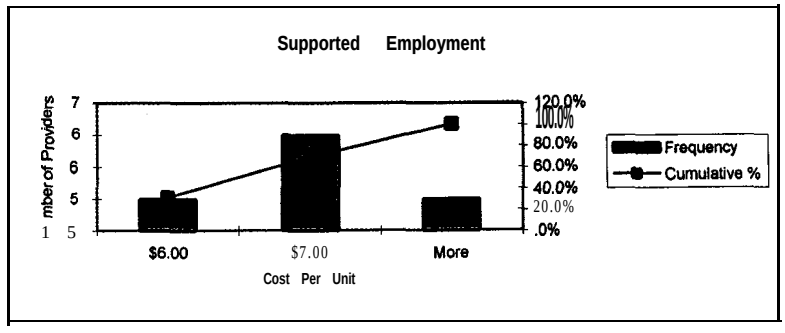
New bin	# Providers	Cumulative %
$ 21.00	4	17.39%
$ 24.00	7	47.83%
$ 29.00	7	78.26%
More	$ 5	100.00%
Mean	$ 25.12	
Min	16.28	
Max	$ 31.20	
St. Dev.	$ 4.61	



New bin	#Providers	Cumulative %
$ 135.00	8	22.86%
$ 150.00	9	48.57%
$ 165.00	12	82.86%
More	6	100.00%
Mean	$ 146.41	
Min	$ 109.60	
Max	$ 166.67	
St. Dev.	$ 17.18	



New bin	# Providers	Cumulative %
$ 6.00	5	31.25%
$ 7.00	6	68.75%
More	5	100.00%
Mean	$ 7.97	
Min	$ 4.88	
Max	$ 21.48	
St. Dev.	$ 3.98	



Commonwealth of Kentucky

Direct Care Compensation Data

State ID	State Name	Market Rate for DD Nursing Care				Market Rate for DD Habilitation Work				Market Rate for DD Personal Support Work				Competing Employers		
		25th Percentile	50th Percentile	Market Average	75th Percentile	25th Percentile	50th Percentile	Market Average	75th Percentile	25th Percentile	50th Percentile	Market Average	75th Percentile	Janitor 50th Percentile	Food Service 50th Percentile	Retail Sales 50th Percentile
AK	Alaska	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AL	Alabama	$17.89	$18.66	$19.01	$19.96	$7.41	$8.23	$8.48	$8.90	$7.76	$8.23	$8.24	$8.67	$8.24	$7.95	$7.52
AR	Arkansas	$18.53	$19.46	$19.78	$20.90	$6.99	$8.18	$8.48	$9.23	$7.34	$8.11	$8.12	$8.58	$8.24	$8.56	$8.58
AZ	Arizona	$18.20	$19.69	$20.30	$21.49	$8.17	$8.85	$8.95	$9.64	$9.16	$9.76	$9.67	$10.21	$9.29	$9.74	$9.47
CA	California	$23.70	$25.12	$25.67	$27.56	$10.24	$11.51	$11.26	$13.52	$9.61	$11.32	$10.59	$12.55	$10.76	$11.44	$9.44
CO	Colorado	$18.27	$19.77	$19.95	$21.64	$8.58	$8.98	$9.07	$9.40	$8.64	$9.45	$9.39	$9.96	$8.43	$8.74	$8.41
CT	Connecticut	$20.62	$22.62	$22.88	$25.50	$8.83	$9.62	$10.22	$11.31	$9.47	$10.23	$10.46	$11.06	$9.64	$9.67	$9.39
DC	District of Columbia	$17.70	$18.90	$19.00	$20.30	$9.28	$9.90	$10.69	$11.17	$8.50	$9.08	$9.10	$10.00	$9.30	$8.38	$9.54
DE	Delaware	$18.28	$19.71	$19.92	$20.89	$8.93	$9.90	$10.64	$10.92	$8.74	$9.11	$9.24	$10.14	$9.60	$9.54	$9.48
FL	Florida	$18.99	$19.59	$20.07	$21.16	$8.24	$8.69	$9.00	$9.25	$8.31	$9.04	$9.12	$9.61	$8.04	$7.97	$8.61
GA	Georgia	$18.95	$20.00	$20.61	$21.33	$7.46	$8.18	$8.23	$8.70	$8.07	$8.46	$8.79	$9.08	$8.82	$7.95	$9.37
HI	Hawaii	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	Iowa	$17.42	$18.48	$18.43	$19.60	$8.25	$9.00	$9.12	$9.72	$8.32	$9.24	$9.20	$9.83	$9.59	$9.06	$7.70
ID	Idaho	$18.14	$19.37	$19.93	$21.38	$8.53	$9.18	$9.32	$9.75	$8.01	$9.60	$9.60	$10.31	$9.77	$9.28	$8.24
IL	Illinois	$17.76	$19.88	$19.90	$22.04	$8.45	$9.05	$9.65	$10.97	$7.90	$9.00	$9.22	$10.25	$10.48	$9.77	$8.96
IN	Indiana	$18.45	$19.55	$19.74	$20.82	$8.11	$9.22	$9.07	$10.01	$8.50	$8.99	$9.22	$9.64	$9.52	$9.13	$8.41
KS	Kansas	$18.36	$19.31	$19.18	$20.19	$7.86	$8.48	$8.68	$9.84	$8.55	$9.82	$9.60	$10.46	$9.47	$9.24	$8.45
KY	Kentucky	$16.23	$17.52	$18.10	$20.05	$8.20	$9.15	$9.52	$9.79	$8.39	$8.89	$9.02	$9.29	$9.49	$8.74	$8.91
LA	Louisiana	$18.35	$19.42	$19.64	$20.64	$6.76	$7.46	$7.75	$8.35	$7.07	$7.77	$7.80	$8.56	$8.13	$8.63	$7.98
MA	Massachusetts	$20.40	$22.27	$22.95	$25.35	$8.83	$9.62	$10.22	$11.31	$9.42	$10.29	$10.45	$11.18	$11.20	$9.67	$9.90
MD	Maryland	$18.52	$20.49	$20.33	$21.69	$9.13	$9.90	$10.49	$10.82	$8.89	$9.46	$9.42	$10.43	$9.36	$9.60	$8.67
ME	Maine	$19.69	$21.92	$21.35	$23.55	$8.83	$9.62	$10.22	$11.31	$9.17	$9.79	$10.02	$10.67	$10.03	$9.67	$9.49
MI	Michigan	$17.96	$19.60	$19.52	$20.63	38.63	39.87	$10.12	$10.87	$8.60	$9.13	$9.21	$9.50	$10.27	50.13	59.34
MN	Minnesota	$19.02	$20.38	$20.69	$22.68	$8.26	$9.05	$9.25	$10.64	$9.56	$9.86	$10.20	$10.83	$10.28	$9.74	$9.14
MO	Missouri	$17.45	$18.83	$18.86	$19.97	$8.25	$9.00	$9.12	$9.72	27.97	$8.82	$9.19	$9.86	$10.38	$9.06	$8.77
MS	Mississippi	$18.05	$19.02	$19.06	$20.11	$7.66	$8.21	$8.43	$8.88	$7.85	$8.18	$8.30	$8.76	$8.88	$7.95	$8.50
MT	Montana	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NC	North Carolina	$17.10	$19.13	$19.23	$21.00	$7.61	$8.25	$8.55	$8.95	$7.45	$8.49	$8.57	$9.82	$8.79	$7.95	$8.73
ND	North Dakota	$18.09	$19.31	$19.65	$21.13	$7.93	$8.65	$8.78	$9.84	$8.55	$9.82	$9.60	$10.46	$9.74	$9.24	$8.04
NE	Nebraska	$17.72	$18.91	$19.05	$20.20	$7.93	$8.65	$8.78	$9.84	$8.77	$9.89	$9.85	$10.68	$9.74	$9.24	$8.60
NH	New Hampshire	$13.37	$14.98	$15.19	$17.20	$8.83	$9.62	$10.22	$11.31	$9.30	$10.13	$10.37	$11.08	$9.88	$9.67	$9.65
NJ	New Jersey	$19.06	$20.55	$20.86	$21.46	$8.93	$9.90	$10.64	$10.92	$8.81	$9.12	$9.51	$10.02	$9.22	$9.60	$10.18
NM	New Mexico	$17.94	$19.77	$20.10	$21.68	$8.58	$8.98	$9.07	$9.40	$9.13	$9.48	$9.50	$9.96	$8.43	$8.74	$8.95
NV	Nevada	$19.64	$20.76	$21.55	$23.15	$9.03	$9.83	$9.90	$10.55	$9.11	$9.70	$9.75	$10.46	$11.26	$9.34	$9.88
NY	New York	$19.20	$21.54	$22.28	$24.20	$8.90	$10.02	$10.87	$12.39	$8.96	$9.62	$10.03	$10.85	$10.96	$9.62	$9.23
OH	Ohio	$18.14	$19.69	$19.77	$20.95	$8.63	$9.87	$10.12	$10.87	$8.44	$9.01	$9.26	$9.89	$9.44	$9.32	$8.25
OK	Oklahoma	$18.35	$19.42	$19.64	$20.64	$6.99	$8.18	$8.48	$9.23	$8.02	$8.30	$8.68	$0.18	$8.13	$8.63	$9.30
OR	Oregon	$20.48	$21.93	$21.95	$23.04	$10.09	$11.06	$11.28	$11.96	$9.06	$11.05	$10.75	$11.89	$10.98	$10.53	$9.09
PA	Pennsylvania	$18.17	$19.62	$19.60	$20.64	$8.80	$9.65	$10.22	$10.54	$8.47	$9.25	$9.20	$10.03	$9.80	$9.68	$8.88
RI	Rhode Island	$21.22	$23.07	$23.56	$25.64	$8.83	$9.62	$10.22	$11.31	$9.30	$10.13	$10.37	$11.08	$10.13	$9.77	$10.18
SC	South Carolina	$18.36	$19.24	$19.65	$20.83	$7.73	$8.31	$8.55	$8.95	$8.04	$8.60	$8.73	$9.40	$8.79	$7.90	$9.14
SD	South Dakota	$18.09	$19.31	$19.65	$21.13	$7.93	$8.65	$8.78	$9.84	$8.55	$9.82	$9.60	$10.46	$9.74	$9.24	$8.60
TN	Tennessee	$17.69	$18.55	$18.61	$19.71	$7.73	$8.31	$8.55	$8.95	$7.91	$8.33	$8.39	$8.97	$9.16	$7.98	$8.89
TX	Texas	$18.17	$19.61	$19.81	$20.59	$7.16	$8.56	$8.70	$9.40	$7.42	$7.98	$8.10	$8.52	$8.10	$8.68	$9.28
UT	Utah	$18.01	$19.39	$19.95	$21.43	$8.65	$8.98	$9.07	$9.15	$9.13	$9.48	$9.50	$9.96	$8.69	$8.74	$9.33
VA	Virginia	$17.73	$19.01	$19.30	$20.83	$7.66	$8.31	$8.55	$8.95	$8.01	$8.60	$8.84	$9.01	$8.61	$9.63	$9.02
VT	Vermont	$13.37	$14.98	$15.19	$17.20	$8.83	$9.62	$10.22	$11.31	$9.30	$10.13	$10.37	$11.08	$9.88	$9.67	$9.47
WA	Washington	$21.05	$23.02	$22.93	$24.58	$10.09	$11.06	$11.28	$11.96	$9.56	$10.87	$10.46	$11.68	$11.21	$10.53	$9.96
WI	Wisconsin	$18.58	$19.51	$19.84	$21.41	$8.80	$9.25	$9.42	$9.87	$8.52	$9.05	$9.43	$9.97	$9.62	$9.41	$8.61
WV	West Virginia	$17.85	$19.33	$18.96	$19.89	$8.20	$9.15	$9.52	$9.79	$8.40	$9.08	$9.20	$9.58	$9.63	$8.40	$8.49
WY	Wyoming	$18.14	$19.37	$19.93	$21.38	$8.53	$9.18	$9.32	$9.75	$8.01	$0.60	$9.60	$10.31	$9.52	$8.96	$7.41
NTL	National Da&	$18.52	$19.78	$20.19	$21.61	$8.28	$9.15	$9.55	$10.47	$8.24	$9.14	$9.37	$10.26	$9.34	$8.61	$9.41

Turnover Statistics and Nonstatutory Fringe Benefits Data

Region	Annual Turnover Rates in Home Health: Nursing Care	Habilitation Work	Personal Support Work	Actual Cost of Nonstatutory Fringe Benefits: Nurses and Therapists
New England	13.14%	9.50%	23.86%	19.38%
Middle Atlantic	17.48%	18.24%	22.11%	14.66%
South Atlantic	21.60%	19.85%	20.83%	23.62%
East North Central	21.66%	17.23%	28.78%	19.05%
East South Central	27.49%	30.20%	32.65%	14.24%
West North Central	18.14%	24.27%	19.03%	16.57%
West South Central	27.81%	35.33%	32.32%	16.14%
Mountain	23.77%	23.63%	59.44%	16.80%
Pacific	16.84%	35.92%	24.94%	18.82%
National Average	21.01%	23.69%	27.79%	18.67%

*As a Percentage of Base *Salary*

	Inventory	SD Definition- CEO	SD Definition- Emp	People First Lang.	Org. Support People First Lng.	Orientation with SD Principles	Training with SD Principles	Job Desc. with SD Principles	Consumer/Family Involve Hiring	Owned Sites Barrier?
Community Provisions		Aware of basic principles, but at elementary level.	Very limited knowledge	Yes	Yes		Yes	Traditional	Yes; individuals and families may choose and/or veto service coor and direct care staff	
Everyday Matters	X	Like Supported Living Program (people gel a certain amount of money & they can buy what they wish?)	No Understanding	Taught	Somewhat Supportive	concept: Working for Consumer	Agency issues pay so staff knows who they report to.		No except for respite & com. Living// agency finds someone else	No
CAKY- Winchester	NOTES	An initiative to empower individuals with DD to create a quality of life they desire for themselves. Systemically, the waiver system has to allow individuals and their cirlce of support to use Medicaid waiver funding to best meet the individual% needs.	Individual has an opportunity to participate in the hiring process for that person. Direct Care workers should be in the mindset that they are there to assist this individual to lead a full and productive life.	Not Familiar	Yes	Unsure	Many staff would like to see change and are ready for it.		Not happening	Omership by the agency is a barrier it staffed apartments is the only option for consumers
Laurel Springs										
Life Skills	X	Choice and say-so about their own lives, reasonable funding streams, responsibility and accountability, person first. release of professional control	All the way to residential staff. required PCP training, inservice on outcomes. **ISP process very person centered, regulations for SCL prevent pure PCP and needs to be changes.	Very Familiar	Yes	Brochure/ 53 hours of orientation including video	Survey completed: they have seen major improvements in this area	Traditiont al	Yes; individual arent or others aig and vested in brick & mortar. providers.	parent or others are
Louiseville Diversified Services		The money is with the person and they make the choices.	Freedom of Choice and the ability to choose among all providers.	Yes	Yes	Yes	Yes	Traditional	Becoming more involved in process.	
North Kentucky Community care	X									
Pathways		Moderate knowledge of priciples, use PCP and some choice of services & support coordination.	Limited knowlegde	YES	Yes at all levels			No	No with exception of a few choice providers under SCL	

	Inventory	SD Definition- CEO	SD Definition- Emp	People First Lang.	Org. Support People First Lng.	Orientation with SD Principles	Training with SD Principles	Job Desc. with SD Principles	Consumer/Family Involve Hiring	Owned Sites Barrier?
Penny Royal	X	Empowering me individual. individual controls resources, family letting go.	Employees have little if any knowledge d SD, familiar with philosophy of choice.	Exec Dir.: Not familiar; described it as bureaucratic bull & political correctness	MR/DD Director was familiar with the term "removing labels" and demeaning language	Embrace concepts but not the language	Embrace concepts but not the language		Effort made to accommodate individual choice but options are limited; Ombudsman on contract to help resolve disputes.	Yes; there would be some operational issues
ResCare	X	Ensuring that each parson who seeks supports and services has the control to choice what. when, where, and who. This includes control of financial resources, "staffing", housing, and all other facets of life currently influenced by slots. funding inflexibility, etc.	Absolutely. As control and responsibility would rest with the person/family the direct care worker would need to understand and perform to expectations of me person who has hired them. In addition, me direct care worker would truly need to understand supporting me person in their daily life versus directing the life as they want me person to live.	Yes	Yes	Yes	Yes	Inconsistent with job desc. And performance evaluations	Sporadically involved	Control of personal money is an issue. Many people are living in situations that are on the edge or beyond their means.
Seven County Services										
Strategic Partnerships	X	Meet participants needs, rather than our value system; consumer choices services & supports; not simply fit in slot or program	Choice & control over services & supportive emphasized in staff-orientation. Outcome training provided in cooperation with DD Council. Sell-assessment in 25 categories used preliminary to developing person-centered plan (ISP)	Yes	Followed-up in practice	Yes	Yes	Traditional	May choose from provider list at any time.	No
Supported Living of North KY										
WATCH										
CAKY- Bluegrass		They do PCP which is individually driven and this is relayed to staff.	Limited knowledge	Yes	Yes	Yes	Yes	*Implicit in* description	Occasionally involved	
Dreams With Wings		People determining what services they get. who they live with. where they live. what they do, and what they spend their money on.	Shared with all employees. A recent all day retreat focused on SD and other issues d philosophy. Unity d purpose is important.	Yes	Yes	Yes	Yes	Traditional	Yes	
Cedar Lake		It is an understood concept, but not yet practiced.	Senior management is aware ot me principles of SD. Direct Care staff have not yet had much exposure.	No	No	No	No	No	No, but family & consumer input is sought in planning and decision making.	

	Pay Rate	Benefits	Budget Knowledge	Internal Budget Knowledge	Mission tied to SD	Org. Structure for SD	Needed to support SD	BOD Awareness	BOD Support of SD	Happy or Outcomes'	Consumer Influence in Planning	Facilitating Plannning Mtg.
Four Rivers BH (notes)	$13,500 DC $20,000 Sup Coor	Competitive	Community Living Staff, Work Habilitation Staff	Well Known	Yes	Yes	Depending on the model that is rolled out.	Yes	Yes	Outcomes being measured	Consumer complete control	Consumer
Kaliedescope	$8.50 - $9.00	Excellent	Direct Care	Direct cam workers do not know internal/ Ownership knowledge	Yes	Yes	Accounting system would support SD	Yes	Yes	Measuring Happy	ComCare responsible for plans	N O
New Foundations	$6.50 - 8.00	100% Insurance	Supervisor Staff	Home Provider staff	Yes	Yes		Yes	Yes	Both	High level of influence	Support Coo'
Mountain CompCare	Decent; direct cam begin at minimum wage	Decent	Direct Care not interested, even middle management not interested.	Direct Care not interested. even middle management not interested.	Yes	Yes	Need to get more involvement outside the agency, need to make changes to deal with individualized budgets	Yes; majority know about SD	Mission includes SD statements	Use James Garden 'The Council"self study on outcomes.	25% or less have active involvement from families; they are In control of who they want them	Consumer an family never facilitate
Kentucky River Com Care												
CAKY- Green River	recent increase		Direct Care; Not happy with SNAP tool	Direct cam	Fits nicely, supports core values	Yes	Minor management/ training/ budget development	Yes	Yes	Not measuring outcomes/ limited budget then real choices are not always possible		
CommuniCare			Direct Cam	Program Managers	Yes	Yes		Limites	Yes	Both	Minimal: PCP provided to individuals	Sup Coor.
Community Presence			Direct cam	Admin Team		Yes	Problem with families			Happy	Consumers	Sup Coor.

	Pay Rate	Benefits	Budget Knowledge	Internal Budget Knowledge	Mission tied to SD	Org. Structure for SD	Needed to support SD	BOD Awareness	BOD Support of SD	Happy or Outcomes	Consumer Influence in Planning	Facilitating Plannning Mtg.
Community Provisions			Direct Care	Direct Care						Happy	Heavy Involvement	Service Coor.
Everyday Matters	Pay more then ResCare											
CAKY- Winchester	Pay much higher in Vermont	Benefits much greater In v - t	Support Coordinators		N C	Yes	The agency may only provide some waiver services and not all services.	Unknown		No: Measure goals and standards of other people not of the individual themselves	No	More control is needed. Some family involvement.
Laurel Springs												
Life Skills	slightly below market; Direct cam $7.75 per hour.	Profit sharing. 1% Bonus	service coor.	supervisors and admin staff, not direct care	Y e s	Yes	Yes; have the capacity but would need to adapt billing and information system	Need extra training/ they are aware	more training	Yes- included in vision statement		
Louiseville Diversified Services			highest senior management	all stall	Yes	Yes		Yes	Yes	Outcomes being measured	As much as they choose	sup Coor.
North Kentucky Community cam												
Pathways			service coor.	Program Directors a Managers				Limited Knowledge		Outcomes being measured	Consumer Choice in Living	sup Coor.

	Pay Rate	Benefits	Budget Knowledge	Internal Budget Knowledge	Mission tied to SD	Org. Structure for SD	Needed to support SD	BOD Awareness	BOD Support of SD	Happy or Outcomes	Consumer Influence in Planning	Facilitating Plannning Mtg.
Penny Royal	Competitive	Excellent	Known top to bottom	Regional goals are published and available as "open" book	Yes; everything focuses on choice	Yes	More resources are necessary.	Not aware of the "busy words" but policies and procedures are implicit rather than explicit		Use customer survey forms provided by the Mental Health Corp of America		
ResCare	$6.50 $9.50	competitive	direct supervisor of the direct care staff	Home manager	Yes	Yes	Organizational change depends on the service requested and national trends.	Yes	Yes	Quality assessment tool measuring outcomes and customer satisfaction tool measuring happy.		
seven County Services												
Strategic Partnerships	Comprable with area	Direct Care staff can not afford health care.	service coor	billing clerks	No	More training needed, clarify expectations, need to comply to regulations, need corporate support		Unknown	Chain of command would need to be in support	Measured to some extent		
Supported Living of North KY												
WATCH												
CAKY- Bluegrass			Limited Knowledge	Corporate	Yes	Yes		Corporate level	Limited knowledge	Both	ISP process	Sup Coor.
Dreams With Wings			Most employees	Senior Management	Yes	Yes	More infrastructure support	Yes	Yes	Outcomes	Actively encouraged to attend and participate	Some consumer control/ typically provider staff
Cedar Lake			Need to know basis	Need to know basis	No			No	Unknown	Happy	Limited Influence	Senior staff

	Financial Control?	Fiscal Intermediary/ Service Brokerage	Marketing Reflect SD	Community Org. support SD	Community Org Change For SD	Provider Changes for SD?	State Changes for SD?	
Four Rivers BH (notes)	Limited; consumer has choice in provider	Yes in Supported Living Program	Not sure	Public schools, grants, House Bill 144	Currently good relationship with community	Change in stall to accommodate personal budgeting, need to work cloder with other organizations	Regulations and monitoring would need to change depending on model, slow evolution process	
Kaliedescope	No	No		Yes	More partnership among providers, working together to reach goals of indivudals	Offer competitve employment & supportive employment	embrace persons with disabilities as individuals, relabel the community, offer sensitivity training, employ their own self-directed principles	
New Foundations	High level of involvement		Brochure	No	Provider relations needs to improve.			
Mountain CompCare	Not much involvement	45 individual budgets; agency has a coordinator of supported living	Yes materials that reflect SD; brochure	Need work in this area.	More education needed	How does the provider support the existing system while changes are being made?	The standards that are currently being used need lo be more flexible to support true change. Need to keep quality providers, training with families, transportation changes.	
Kentucky River Com Care								
CAKY- Green River			Not really/ changes are needed	MR/DD involvement very strong in SD// those on mental health side are very weak.	Minor changes/ already working together			
CommuniCare	No	No	No	No		Pay for employees, trainging needed for SD. transportation issues	Need lo be more flexible with the current system in allocating resources. need io follow through with proposal of pilot.	
Communlty Presence	No	No	No: updating	No	Having a good attitude and being willing to participate/ change in overall attitude	training of all staff, consumer, parents	Limited flexibility and availability of funds.	

	Financial Control?	Fiscal Intermediary/ Service Brokerage	Marketing Reflect SD	Community Org. support SD	Community Org Change For SD	Provider Changes for SD?	State Changes for SD?	
Community Provisions	No	No	No	Local schools	More training and education	Resources	support from DMR and more resources	
Everyday Matters								
CAKY- Winchester	No	No	Unknown	SD Advocacy org of Vermont	Develop Partnerships in order for individuals to become integrated in the c-nity.	Philosophy Change	Allow individual control of funding, shift to individual centered process, advocacy resource needs to be available, provide more options, need to begin thinking 'out of the box' and 'raise the bar'. an action plan needs to be developed	
Laurel Springs								
Life Skills			Pamphlets/ SCL brochure/ positive news stories/ monthly column	ANCOR, CARF, TASH (past), AAMR	Improve communication with other organizations.			
Louiseville Diversified Services	No	No	Yes	Yes		Lack of providers and mat choice,	SNAP tod needs to change, more training of SD to families. consumers. c-nity	
North Kentucky Community Care								
Pathway8	No control	No	No	Yes	Cultural barriers. family perception reflects caution	Budget barriers, need more information and training, knowledge from other states w/ SD programs	heavy caseloads and budget barriers, need to relax rules, more visible support role	

	Financial Control?	Fiscal Intermediary/ Service Brokerage	Marketing Reflect SD	Community Org. support SD	Community Org Change For SO	Provider Changes for SD?	Stete Changes for SD?	
Penny Royal			Brochures	KARP, National Council of Mental Health Centers supports principles	Unknown at this time.			
ResCare			Yes considering changes for more SD	KARR, AAMR, ANCOR	More networking and partnerships with the community			
Seven County Services								
Strategic Partnerships								
Supported Living of North KY								
WATCH								
CAKY- Bluegrass	No	No	Yes	Yes		mm-e training needed for overall involved	State Guardianship with limited caseload, reconcile support and eligibility criteria with concepts of SD	
Dreams With Wings	Problematic	No	No	Community-wide fundraising	General lack of family awareness about concepts and choices available	Technical assistance in working with individuals that have challenging behavior		
cedar Lake	No	No	No	Family forums, social events	Lack of family awareness	Lack of trust with State,	Underfunded system, needs to establish and follow through with pilot program	

	Inventory	# of Consumers	Region	Private/ NonProfit	Services	# Locations	# Employees	# Employee P/T	# Employee Fr	Turnover Rate	Annual Budget/Service	Total Budget	Waiver % Fundlng
Kentucky River ComCare	X	90	Hazard	Profit	Residential 21, Com. Hab. 60-70, Respite 75%. sup. Employ 2, Sup Coor. 90	12	50	0	50	50%	$1 .0M SCL. $385K St. Gn. Funds, $555K Grants	$1.94M	
Laurel Springs													
Life Skills	X	700	Bowling Green	Non-Profit	Early Intervention 250, Respite 100, CH 190, Sup Living 31. Ind. sup 40, sup Coor. 260, Crisis 35, Sup Employ 30, Sup fo Corn. Living 75	12	157	34	123	49%	CH $446,298, Sup Living $301,190. Ind sup $232.507, Reg. Sup Coor. $225,000, Crisis $152,993, Sup employ $133,200, PASRR Spec Sew. $130,744, Gmup Home $103,000, Respite $95,000, Early Intervention $61,000, SCL $3,126,145, DVR $200.000	$7,943,195	39%
Louiseville Diversified Services	X	300	Louiseville	Non-Profit	Day Program 50.55 Work Crew, 190 Comp. Employ	13	65	10	55		$2.2M		45%
North Kentucky Community Cant	X												
Pathwavs	X	600	Ashland	Non-Profit	Early Intervention 375. Corn Hab 160. Sup Employ 45. Corn Resid 39, Sup Coor, Sup Living, Respite	20	240				$6-7 M		
Penny Royal													
ResCare	X	700	Statewide	Profit	Family Home 50, SCL 560.. Impact Plus 20. ICF/MR 136, Group Home 6. Employ 400, Sup Coor 400	190	1200	335	665	60%	$47M		$36.5M
Seven County Services													
Strategic Partnerships													
Supported Living of North KY													
WATCH													

	Inventory	# of Consumers	Region	Private/ NonProfit	Services	# Locations	# Employees	# Employee P/T	# Employee FT	Turnover Rate	Annual Budget/Service	Total Budget	waiver % Funding
Four Rivers BH (notes)	X	700	Paducah	Non-Profit	First Steps 319. Sup Living 53, CH 40 facilities, Sup Employ 50	40				10%			
Kaliedescope	X	95	Louiseville	Profit	Com. Hab 5, structured day 90. OT 10, PT 6. ST 12, Counseling 10. Sup. Coor. 5, C&e Mang. 10	1	31	6	25	37%- 2000 18% YTD	$1,174,392		96.40%
New Foundations	X	5	London	Profit	Sup Coor.. BH, PT, OT, Sup Employ, CH, Staffed Residence	3	10						
Mountain CompCare		300	Prestonburg	Non-Profit	Com Day Program, PreVoc Skills,	7				70%			
CAKY- Winchester													
CAKY- Green River			Owensboro										
CommuniCare	X	600	Elizabethtown	Non-Profit	Corn. Hab 256, Residential 49, Comp Employ 15 Sup Employ 89	20	300				$15M		$6M
Community Presence	X	23	Grayson	Non-Profit	Residential 23, Pub Sch 20, SCL 4, Sup Coor 6, Com Hab, Therap Child Sup, Crisis Stab.	6	65						
Cummunity Provisions	X	9	Manchester	Profit	Supported Living 6. In-home support Respite, Sup. Coor, Corn. Hab., BH Support, Spch Therapy, OT, PT	4	13				$800K		
Everyday Matters	X	18	Frankfort	Protil	Residential 14, Corn Hab. 16, Respite 2, Corn. Living 3. BH Support 3, Sup Coor. 15	7	26	6	20	25%	$1.2 M	$12 M	100%

	Inventory	# of Consumers	Region	Private/ NonProfit	Services	# Locations	# Employees	# Employaa P/T	# Employee FT	Turnover Rate	Annual Budget/Service	Total Budget	Waiver % Funding
CAKY- Bluegrass	X	63	Frankfort	Profit	Sup Coor., Residential, Com Living Sup. PT, OT, Speech, Com Hab, Sup Employ, Respite, BH Manage	22	125				$2.9 M		
Dreams With Wings	X	19	Louiseville	Non-Profit	Stalled Residence 4, PT Stall Residence 4. In-home Services 3. Outreach/Leisure 10, Employ Services 2	5	13	0	13		$800,000		
Cedar Lake	X	150	Louiseville	Non-Profit	Residential 76. Group Home 16, Sup Living, Indep. Living, In-home Sup.	16	200	0	200		$8.0M		

	ICF/MR % Funding	Private % Funding	Owned Locations	Leased Locatfons	Entry Pay	Benefits	Effective Ben. Date	Mission Statement	Business Plan	# B O D	BOD Makeup	Advisory Board	Satisfaction survey	outcome survey
Four Rivers BH (notes)			40	0	$13,500 DC $20,000 Sup Coor	Competitive		Yes	Yes	Yes	Family members, public leaders		Yes	Yes
Kaliedescope	3.66%		1	0	$8.50- $9.00	health, disability, vac, sick, profit share, vestment period, bonus	90 days	Yes	SOD Minutes	2	Owners	Yes	Yes	Yes
New Foundations			2	1	$6.50 • $8.00	100% Insurance, Vac.		Yes	Yes	Yes	Owners, Pastor, Lawyer, MD, Parent	No	Currently developing	
Mountain CompCare			2	5	Competitive	Decent		Yes	Yes	Yes		Yes	Yes	Yes
CAKY- Winchester														
CAKY- Green River														
CommuniCare			15	5	$6.00	27%		Yes	Yes	Yes	26 Members	N o	Yes/ Annual	ISP Tool
Community Presence			6	0				Yes	Yes	Yes		Human Rights Committee	Parent Sat. Survey	N o
Cummunity Provisions			0	4				Yes	Yes	Yes		No	Yes	
Everyday Matters			0	7	$7.50-$8.25	Sick. Vacation, Dental, Health		Yes	Developing	Yes: 5	Attorney, Parent, Consumer	No	Yes	Quality Improvement Plan/ Outcomes on Safety, etc.

	ICF/MR % Funding	Private % Funding	Owned Locations	Leased Locations	Entry Pay	Benefits	Effective Ben. Date	Mission Statement	Business Plan	# SOD	SOD Makeup	Advisory Board	Satisfaction Survey	Outcome Survey
Kentucky River ComCare			5	7	$7.50			Yes	Yes	15 ppl.	No Consumer, No Family	No	Not accredited Center, send out questionnaire /year	Quality Assurance Measures
Laurel Springs														
Life Skills	24%	37%	6	6	$7.00 - $725	Yes; Vac, Sick. Health, Bereavement, LTC. Personal. Retirement		Yes	Yes	Yes		No	Yes	DMR & SCL review OA plan
Louiseville Diversified Services	45%	10%						Yes	Yes	Yes	Family, community, leaders from community	No	IDS Tool	IDS Tool
North Kentucky Community Care														
Pathways			12	6				Yes	Yes	Yes		No	Yes	IPP
Penny Royal														
ResCare	$10M	$360K	4		$6.50-$9.50	Health, 401K, Sick, Vac., Hol, LTD, Life, Dep Care, Dental	6 months except health 3 months	Yes	Yes	Yes	Owners, Community Members, Founder. CEO	Each CAKY has Consumed Family Council	Yes	Internal Quality Assurance used
Seven County Services														
Strategic Partnerships														
Supported Living of North KY														
WATCH														

	ICF/MR Funding	% Private Funding	owned Locations	Leased Locations	Entry Pay	Benefits	Effective Ben. Date	Mission Statement	Busi Pla		BOD Makeup	Advisory Board	Satisfaction survey	Outcome Survey
CAKY- Bluegrass			0	22				Yes		orporate Level		Human Rights Committee	Corporate Office Measures	Measured during PCP Process
Dreams With Wings				4				Yes	Yes	Yes	Owner & Family Members	No	No	No
ceder Lake	$7M	$1M	16	0				Yes	Yes	Yes	Parent Membership	No	Yes	No

	Format for Planning	Planning Facilitator	Planning Finances	Format for Finances	Marketing	Other Marketing Forms	Community Involvement	self-Advocacy	Provider Organizations
Four Rivers BH (notes)		Consumer	Consumer have provider choice. but guardians have too much control		Brochure	Public Forums	House Bill 144. public schools, grants	Parent Advocacy group in past nol sure of current status	House Bill 144
Kaliedescope	Yes	Sup. Coor	No	No	Brochure/ Word of Mouth/ Website	No	No	Headliners! Justice For Ail	KAAD/KRA/ Coalition for Choice/ NCIL/ Voice of Retarded/ BIAK
New Foundations		Agency	Consumer involvement		Brochure/ word of Mouth		No	No	No
Mountain CompCare		sup Coor	Sup Coor	State Format	Brochures		No	No	
CAKY- Winchester									
CAKY- Green River									
CommuniCare		Sup Coor./ Consumer Influence	No	No	Brochure	No	No	No	Yes
Community Presence	Yes	Sup Coor.	No	No	Brochure	Agency has waiting list of 20 clients	No	Yes	No
Cummunity Provisions	Yes	Management/ heavy family involvement	Service Coor.	No	Brochure/ Word of mouth/ local education & community leaders		No	N C	Protection & Advocacy
Everyday Matters	Slate Form & Own Form	Support Coordinator/ Circle of Friends/14 Guardians	Consumer with a little control but not close to MI.	CompCare Services	Brocure/ Letter thru State	Fundraising/Not targeted	Bookstore Poetry Venture	No	AAMR/ANCOR

	Format for Planning	Planning Facilitator	Planning Finances	Format for Finances	Marketing	Other Marketing Forms	Community Involvement	Self-Ad-y	Provider Organizations
Kentucky River ComCare	Mapping Forms		Aimed at services not funds		Marketing Director/ Word of Mouth/List	TV/ Special Olympics/ Show training	No	Consumer on WaitingList Committee	AAMR
Laurel Springs									
Life Skills	ISP	Sup Coor	Reviewed with Consumer	SL, ISG Tool	Brochure	Public Service Annoucement, Newspaper, Radio. Schools, Health Fairs, Word of mouth	Annual Picnic, Open Houses	No	ARC's/ ANCOR/ KARR/ KY Disability Council/ KARP
Louiseville Diversified Services	Yes	Choice of Involvement Level; Sup Coor Lead	Family Involved	COSt Worksheet for SCL	Brochure/ Family Handout	Website/ Fundraising/ TV & Radii	Day of Caring/	CRC (Council for Retarded)	Assoc. for Providers of Sup Employ/ KARR
North Kentucky Community Care									
Pathways		Paid Facilitator/ Support Coordinator	No	No	Brochure	Job Fairs/ Newspaper ads/ public speeches		Protection & Advocacy/ Family Support Groups// No Sell Advocacy Groups currently exist	Disbility Day @ County Fair/ auctions/ family outings
Penny Royal									
ResCare	Yes	Sup Coor.	Unknown	State Format	Brochure	Provider Fair/ Internet/ Letters/ Newspapers/ Word of mouth	Training/ Special Olympics/ Walk A Thons	ARC	KARW ANCOR/ AAMR/ multiple slate organizations
Seven County Services									
Strategic Partnerships									
Supported Living of North KY									
WATCH									

	Format for Planning	Planning Facilitator	Planning Finances	Format for Finances	Marketing	Other Marketing Forms	Community Involvement	self-Advocacy	Provider Organizations
CAKY- Bluegrass	Yes	ISP/ Sup Coor.	No	No	Brochure	Local Radio/ newspaper/ Chamber of Commerce	10 Community Projects per yr./ ranging from Special Olympics to Adopt a Highway	No	KARR, KOC, AAMR
Dreams With Wings	Yes	Provider Staff; strong family involvement	Some Consumer Control		Brochure	Word of mouth	Family Picnic, Community wide Fund Raising	CRC in Louiseville	Provider Local Coalition/ KARR
Cedar Lake		High Level of Involvement- Family 70%; Senior Staff Leads	No	No	Brochure	Fund Raising/ Web-site/ And Report	Sponsored Events/ Family Forums	No	ARC, House Bill 144, ANCOR. KARR

Center For Outcome Analysis National Baseline Data

Over the years, COA has been responsible for visiting, monitoring, and interviewing more than 40,000 individuals about their qualities of life and satisfaction, including more than 6,000 who have moved from institutional settings to community homes. The following table illustrates the magnitude of our person-centered evaluation work over the past 20 years.

Quality Tracking Activities Conducted by COA since 1975

Location	# of People Visited	# of Years	# of Visits	# of Families Surveyed (@ 70 percent)	# of Family Surveys Mailed
AZ	220	1	220	154	154
AR	500	3	1,500	350	1,050
CA	2,240	4	4,051	1568	6,272
CO	350	2	700	245	490
CT	1,330	5	6,650	931	4,655
FL	1,500	1	1,500	0	0
GA	500	1	500	350	350
HI	120	1	120	350	350
IN	300	1	300	210	210
LA	650	9	5,850	455	4,095
MA	260	2	520	182	364
MI	850	1	850	0	0
MN	80	2	160	56	112
NH	606	4	1,400	424	1,697
NH (S-D)	410	5	410	287	287
NJ	690	3	870	483	483
NY	1,250	2	2,500	0	0
NC (TS)	1,100	5	5,500	770	1,540
NC (S-D)	40	1	0	0	0
OK	3,700	5	18,500	2,590	12,950
PA (PLS)	1,156	15	17,340	809	12,138

Location	# of People Visited	# of Years	# of Visits	# of Families Surveyed (@ 70 percent)	#of Family Surveys Mailed
PA (INST)	4,400	1	4,400	3,080	3,080
PA (WAIVER)	1,812	1	1,812	1,268	1,268
PA (PHILA)	600	9	5,400	420	3,780
PA (BLAIR)	200	1	200	0	0
PA (DELCO)	20	1	20	0	0
WASH DC	200	1	200	0	0
NCS	15,035	1	15,035	0	0
TOTALS	**40,119**		96,508	14,983	55,325

Abbreviations: NC (TS) is the North Carolina Thomas S. Longitudinal Study. (S-D) always refers to the Robert Wood Johnson Self-Determination Initiatives. PA (PLS) is the Pennhurst Longitudinal Study. PA (INST) is the 1988 round of visits to all people in public institutions. PA (PHILA) is a series of visits to non-Pennhurst class members in residential settings in Philadelphia. PA (BLAIR) is the Blair County Quality Tracking Project related to self-determination. PA (DELCO) is the Delaware County Self-Determination Evaluation. NCS is the National Consumer Survey of people with developmental disabilities, performed in 1990 under congressional mandate, which was an extensive survey of satisfaction as well as integration, productivity, and independence.

At present, COA is conducting longitudinal data collection and analysis projects as follows:

. Connecticut, Ohio, and Pennsylvania – tracking special education labeling, placement, and expenditure patterns for more than 600,000 individual students over as much as ten years.

. Kansas – tracking the outcomes of closure of one mental health and one mental retardation institution. Client: Kansas Developmental Disabilities Council and Legislative Oversight Committee.

. California – tracking the quality of life impacts of the Coffelt settlement on 2,000 people over a 5 year period. Most of the people are moving out of institutions. Client: California Department of Developmental Services, and the California Superior Court via Protection and Advocacy, Inc.

. Connecticut – performing longitudinal analyses of special education labeling and placement practices, including racial and gender bias, for 63,000 children over an eight year period from 1987 to 1994. Client: Connecticut Developmental Disabilities Council.

- Florida – collecting baseline data for longitudinal studies of changes in Developmental Services Institutions and the ICF/MR program. Clients: The Advocacy Center and the Department of Health and Rehabilitative Services.

- Illinois – studying the outcomes of out-of-home placement services for annual samples of 250 to 500 foster children, their caregivers, and their biological parents. Four years of the study have been completed. Client: Illinois Department of Children and Family Services, via subcontract with Wilson Resources Inc.

- New Hampshire – evaluating the self-determination project's outcomes for 170 people with disabilities over 5 years. Client: The RWJ and the Department of Mental Health and Developmental Services.

- New York – assessing consumer and family satisfaction with health care and related services for 1,200 people with developmental disabilities over a five year period during movement from institutional to community based care. Client: the New York Division of Developmental Disabilities, via subcontract with Columbus Medical Services.

- North Carolina – studying the effects of institutional reform and community placement for 1,100 people affected by the Thomas S. Consent Agreement. The Thomas S. class members have both mental illness and mental retardation, and most were placed in psychiatric hospitals by the judicial system. Client: Thomas S. Section Office, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, via subcontract with University of North Carolina at Charlotte.

- Oklahoma – design and ongoing analysis of a quality assurance monitoring system that has covered 3,700 people for 5 years, and is expected to be permanent. Client: Oklahoma Department of Human Services, Developmental Disabilities Division.

- Pennsylvania – obtaining and analyzing 2 years of Medicaid paid claims for a random sample of 8,000 children eligible for EPSDT services. Client: Public Interest Law Center of Philadelphia, as part of discovery proceedings in the Scott versus Snider case in Federal court.

- National evaluator for a grant from the Administration on Developmental Disabilities to advance and heighten self-advocacy involvement in problems related to the criminal justice system. Client: Public Interest Law Center of Philadelphia.

- National evaluator for a grant from the Administration on Developmental Disabilities to advance and heighten self-advocacy involvement in problems related to the criminal justice system. Client: Public Interest Law Center of Philadelphia.

- Projects completed in the past by COA principals include:

- The design and analysis of the 1990 "National Survey of People with Developmental Disabilities" mandated by the Congress. (This study was the largest such study ever performed and included over 15,000 face to face interviews);

- The Pennhurst Longitudinal Study (which is the nation's best known research on the effects of deinstitutionalization on 1,100 people with severe developmental disabilities, 15 years and still ongoing);

- The Mansfield Longitudinal Study (in Connecticut, 1,200 people, 4 years); strategic planning outcome studies over 3 years in New Jersey, involving more than 500 service recipients;

- Tracking the life trajectories of 600 young people in Louisiana over 10 years as part of the Gary W. suit initiated by the Children's Defense Fund.

Center for Outcome Analysis Sampling Methodology:

The sampling methodology used by The Mercer Team is included in an article published by Dr. Conroy, "Conroy, J. (1995, January, Revised December). *Reliability of the Personal Life Quality Protocol. Report Number 7 of the 5 Year Coffelt Quality Tracking Project."* Submitted to the California Department of Developmental Services and California Protection & Advocacy, Inc. Ardmore, PA. This study of the reliability properties of the PLQ Protocol has investigated test-retest, inter-rater, and internal consistency for many of the most important outcome indicators in the package. The results have shown that basic demographic information and simple quality items are being collected accurately. Furthermore, most of the major indicators and scales display extremely good reliability characteristics. The scales of adaptive behavior, challenging behavior, and choice making are particularly strong.

The way the study was designed produced very conservative estimates of reliability, because test-retest and inter-rater aspects of measurement error were combined. However, it was possible to separate the test-retest from the inter-rater aspects to some degree, following the advice of Devlin (1989). This approach led to three indicators for each important scale:

- The raw correlation, in which test-retest and inter-rater sources of error were combined;
- The pure test-retest correlation (where respondents at Time-l and Time-2 were identical); and
- The pure inter-rater correlation (calculated by a formula that presumes that any error not due to instability over time must be due to lack of agreement across respondents).

The following table summarizes the results of these analyses.

SUMMARY OF RELIABILITY FINDINGS

Dimension	Raw Correlation (Confounded)	Same Respondent (Test-Retest)	corrected (Inter-Rater)
Adaptive Behavior	**0.973**	**0.996**	**0.977**
Challenging Behavior	**0.866**	**0.999**	**0.867**
Choice-Making	**0.859**	**0.983**	**0.876**
Reported Progress on Goals	**0.620**	**0.668**	**0.952**
Day Program Hours	**0.696**	**0.932**	**0.764**
Earnings	**0.668**	**0.999**	**0.669**
Integration Scale	**0.440**	**0.446**	**0.994**
Quality of Life Then		**0.765**	**0.835**
Quality of Life Now	**0.757**	**0.963**	**0.794**

The two columns to the right represent the 'pure' estimates of test-retest and inter-rater reliability. The results are generally very high, indicating acceptable reliability of most of the measures. In addition to the scales represented in the table, data on developmentally oriented services rendered appear to be reliable across time and Visitors.

There are two problems, and both are in the test-retest area. The Reported Progress on Goals does not seem to be as stable as other measures over time (test-retest .668), although it is apparently strong on the inter-rater measure. The second problem is with the Integrative Activities scale, which displays exactly the same problem. Further work with these scales in community settings will be needed. Greater variety in types of class members, types of lifestyles, and types of respondents will be necessary to adequately test these two scales and ascertain the causes of any psychometric weakness.

In summary, this study has supported the inference that the Coffelt project data are generally being collected accurately, objectively, and reliably.

. Conroy, J. (1980). Reliability of the Behavior Development Survey (Technical Report 80-l-l). Philadelphia: Temple University Developmental Disabilities Center. Found reliability of the behavior scales to be above .80, with adaptive behavior even higher.

▪ Conroy, J., Efthimiou, J., & Lemanowicz, J. (1981). *Reliability of the Behavior Development Survey: Maladaptive behavior section* (Pennhurst Study Brief Report No. 11). Philadelphia: Temple University Developmental Disabilities Center. Reexamined the reliability properties of the maladaptive behavior section of the BDS, and found acceptable inter-rater reliabilities and considerably higher test-retest scores.

. Devlin, *S.* (1989). *Reliability assessment of the instruments used to monitor the Pennhurst class members.* Philadelphia: Temple University Developmental Disabilities Center. The goal of this evaluation was to determine the internal consistency, test-retest and inter-rater reliability of the five instruments (BDS Adaptive, BDS Maladaptive, NORM, PQ, GHMS and LS scales) used by Temple University's Developmental Disabilities Center to monitor the progress of the Pennhurst Plaintiff Class members. Twenty-nine class members, who were living in community living arrangements, were randomly selected to serve as the subjects for this study. The data suggests that the majority of these instruments provide a reliable means of monitoring the progress individuals with developmental disabilities. Recommendations are made for improving the reliability of the scales through more structured training of the data collectors. The purpose of the present study was to assess the test-retest reliability, inter-rater reliability, and internal consistency of the instruments used by Temple University's Developmental Disabilities Center for the past 11 years. In 1978 Judge Raymond J. Broderick, who was appointed Special Master in the Pennhurst case, ordered that data be gathered on the status of every individual living in Pennhurst, a state institution for adults with developmental disabilities. This information was then used to plan for the development of community residences for the Pennhurst residents, following the District Court decision to close Pennhurst. Since 1978, the instruments have been used as a means for monitoring the status of the former residents of Pennhurst who are now living in a variety of community residential programs throughout Pennsylvania.

- Fullerton, A. Douglass, M. & Dodder, R. (1996). *A systematic study examining the reliability of quality assurance measures.* Report of the Oklahoma State University Quality Assurance Project. Stillwater, OK. In a nested design across settings and types of people, reliability of the COA adaptation of instruments for Oklahoma was investigated. Reliability on all scales was found to be acceptable, although some items in the health section were not stable over time. Reliability varied significantly from one year to the next, but in general, the levels of reliability were high and the authors concluded that the methodology was worthy of continuation.

. Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. *Research in Developmental Disabilities, Vol. 20, No. 6,* pp. 387-400. Published version of the report is shown above.

. Dodder, R., Foster, L., & Bolin, B. (1999). Measures to monitor developmental disabilities quality assurance: A study of reliability. *Education and Training in Mental Retardation and Developmental Disabilities,* 34, I, 66-76. Report of a conservative exploration of inter-rater and test-retest reliability of seven major scales developed by Conroy et al. Found acceptable reliabilities overall and recommended continued utilization of the scales in quality assurance activities.

. Harris, C. (1982). An inter-rater reliability study of the Client Development Evaluation Report. Final report to the California Department of Developmental Services. Found the behavior scales of the CDER to display acceptable reliabilities, with the adaptive behavior section showing exceptionally high inter-rater reliability.

. Isett, R., & Spreat, S. (1979). Test-retest and inter-rater reliability of the AAMD Adaptive Behavior Scale. *American Journal of Mental Deficiency,* 84, 93-95. Calculated test-retest and inter-rater reliabilities for all domains of the American Association on Mental Deficiency Adaptive Behavior Scale. Part 1 domains evidenced generally adequate estimates of both within- and between-rater variability. The domains on Part 2 of the scale were less reliable than those of Part 1, particularly with reference to inter-rater reliability. The low Part 2 inter-rater reliability coefficients raise questions concerning the use of Part 2 of the instrument.

. Jagannathan, R., Camasso, M., Lerman, P., Hall, D., & Cook, S. (1997). *The New Jersey Clien Assessment Form: An Analysis of Its Stability Over Time.* Newark, NJ: Developmental Disability Planning Institute, New Jersey Institute of Technology. An independent Rutgers University research group adopted the COA instruments to continue study of the deinstitutionalization process begun by COA in New Jersey. The Rutgers group reported high stability (test-retest) and internal consistency for the instruments.

. Lemanowicz, J., Feinstein, *C.,* & Conroy, J. (1980). *Reliability of the Behavior Development Survey: Services received by clients.* Pennhurst Study Brief Report 2. Philadelphia: Temple University Developmental Disabilities Center/UAP. Compared data collected by Temple University group to data collected by Pennhurst human resources staff on the type and amount of services received by people. The Temple group collected data by staff interview plus records scrutiny. The Pennhurst staff collected data by direct observation and time sampling. The definitions of each service differed in some cases, but the total amount of developmentally oriented services received by each person was correlated at the level of .92 between the two methods.